Roma Mental Health Advocacy Project (2015-21)

Self-Evaluation Report

Roma Support Group

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Prepared by

Roma Support Group

Authors

Sarah Zawacki
Daria Ferranti

Contributors

Edyta Gach - Karapetyan
Szymon Glowacki
Marius Daniel Banceanu

Project Management

Sylvia Ingmire
Gabriela Smolinska-Poffley

Contact for information

Roma Support Group
P.O. Box 23610
London, E7 0XB

Email: info@romasupportgroup.org.uk
Website:
www.romasupportgroup.org.uk

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1. Executive summary

This self-evaluation report describes the work of the Roma Mental Health Advocacy Project (herein referred to as the 'Project') funded by the City Bridge Trust from December 2015 to April 2021. Beneficiaries of the Project belonged to Central and Eastern European Roma migrant communities in London. As a consequence of their migrant profile, past experiences of discrimination and cultural beliefs, many members of Roma communities face disproportionate barriers to accessing mental health services and communicating effectively with health professionals. Roma are reported to experience poorer health outcomes ~~when~~ compared to other ethnic minority and socioeconomically disadvantaged groups, and there is evidence of high rates of anxiety and depression in Roma communities, as well as low levels of access to mental health services.

Drawing on Roma Support Group's (RSG's) past casework in the area of mental health advocacy and its strong links with Roma communities in London, the Project was designed to counteract the barriers that Roma face in accessing mental health services and communicating about their mental health. The Project proceeded according to the following aims:

- To increase Roma community members' knowledge and awareness of mental health issues and services
- To improve access to mental health services for Roma community members
- To enhance community members' satisfaction with mental health services
- To improve Roma community members' overall sense of wellbeing
- To support mental health professionals in their work with Roma patients

These aims were associated with a range of Project activities, which included: 1-2-1 mental health advocacy sessions with Roma beneficiaries; peer support group meetings with Roma beneficiaries; direct engagement with health professionals to help them to serve their Roma patients more effectively; Roma cultural awareness training for health professionals; and the production of informational leaflets and materials for both Roma community members and health professionals.

To assess the extent to which the Project's goals have been realised, this evaluation report addresses the following questions:

- What barriers did beneficiaries encounter in accessing mental health services and what steps did they take to manage these?
- Did the peer support model employed by the Project enhance beneficiaries' self-empowerment in accessing mental health services and learning about mental health issues?
- What were the dynamics underlying mental health professionals' uptake and reception of the Project's offer of Roma cultural awareness training?

These learning questions reflect the Project's holistic approach to improving Roma beneficiaries' mental health and wellbeing, which involved a combination of direct mental health advocacy, assistance with health-related benefit applications and engagement with health professionals working with Roma.

In addition to considering the learning questions, this report proceeds according to an evaluation methodology based on:

- 2016-21 monitoring reports
- A questionnaire given to Project staff
- Review of Distance Travelled Forms (DTFs)
- Review of Satisfaction Surveys
- Review of Feedback Forms
- Data from RSG database

This evaluation has found substantial evidence that, over its five-year lifespan, the Project attained its objectives.

2. Background

2.1 The Roma community

Beneficiaries of the Project were from Central and Eastern European (CEE) Roma communities living in London. To understand the mental health perceptions and experiences of this group, it is vital to first acknowledge the UK Roma community's ethnic identity, migrant profile and the conditions of restricted access to public services that beneficiaries faced in their countries of origin. 'Roma' refers broadly to a diverse population comprising approximately 10 million people globally. The Roma are believed to have origins in the Indian subcontinent, with the largest Roma populations now concentrated in the CEE countries of Bulgaria, Hungary, Romania and Slovakia (European Commission, 2014; Council of Europe, 2012). Roma communities are spread across Europe, and have numerous distinct tribal affiliations, speak a wide variety of languages and adhere to a number of different religious belief systems (Matras, 2014; Cook et al., 2013; Council of Europe, 2012; Ringold et al., 2005). The Roma are the largest ethnic group in Europe without the support of their own state, which has, in many cases, contributed to their lack of recognition as an ethnic minority (Bartlett, Benini & Gordon, 2011; Silverman, 1995).

Throughout their history, the Roma have faced marginalisation and subjugation as they came into contact with other groups. Commonly viewed with suspicion by non-Roma, Roma people have been enslaved, abused and forcibly expelled during their centuries of movement throughout Europe (Matras, 2014). Roma were also persecuted by the Nazi regime, with an estimated 600,000 Roma murdered by the Nazis and their collaborators in the Holocaust (Silverman, 1995). Coercive and involuntary sterilisation practices in communist Eastern Europe (and post-communist Slovakia) targeted Roma women, through which they were either offered monetary payment if they agreed to sterilisation, or sterilisation was performed without consent in conjunction with other medical procedures (Holt, 2005; Silverman, 1995).

In addition to these instances of direct deprivation of rights, Roma are disadvantaged through discriminatory governmental policies or institutional operating frameworks (Cahn, 2007). When nomadism was made illegal in Czechoslovakia in 1958 and in Poland in 1964, Roma people were forced to move into permanent accommodation and were thus deprived of their traditional way of life and right to express their culture (Silverman, 1995). Following this forcible settlement, there is often clear physical separation between Roma populations and other social groups, with Roma living in poor quality accommodation and lacking ~~of~~ access to basic sanitation facilities (Eurofound, 2012). Schools in Eastern Europe engage in systematic misdiagnosis of learning disabilities to justify disproportionate placement of Roma children in special needs classes, even when they have no special needs (FRA, 2018c).

In a UK context, many studies describe the needs of Roma in conjunction with Gypsies and Travellers, which fails to address key distinctions between these groups (particularly in the areas of health, education and housing). To understand these distinctions, it is vital to acknowledge that the Roma in the UK are a migrant community, while Gypsy and Traveller communities have lived in the UK for centuries (Scullion & Brown, 2016). As such, Roma face particular challenges related to language barriers, navigating UK public service systems and ensuring security of their immigration status, all of which can have marked consequences for Roma community members' mental health (Warwick-Booth et al., 2017).

Narrowing the focus further to this report's London context, the Roma population of London is conservatively estimated at 34,000 (Brown, Scullion & Martin, 2013). RSG works predominantly with members of Polish, Slovak and Romanian communities, and these nationalities comprise the bulk of Project beneficiaries' national identities. RSG's service users arrived in the UK in two periods: first in the 1990s as asylum seekers fleeing discrimination in their CEE countries of origin, and subsequently as economic migrants following the 2004 and 2007 EU accessions. Roma communities in London are concentrated in East and North East London (London Boroughs of Newham, Redbridge, Barking & Dagenham, Waltham Forest, Haringey and Enfield), with additional areas of Roma population in West London and North West London (Hammersmith & Fulham, Brent, Ealing and Westminster). Only two of these local authorities (Haringey and Ealing) specifically include CEE Roma in their health needs assessments (as of summer 2018). The remaining local authorities make no reference to CEE Roma.

2.2 Barriers to health care access

Much of the current research on Roma health comes from a European context, with relatively few studies focusing specifically on the health of Roma migrants in the UK. Studies from Europe reveal substantial systemic barriers to access to health services for Roma patients, which in turn contribute to significantly poorer health outcomes for members of Roma communities (European Commission, 2014). Barriers to healthcare can arise from lack of identification documents, physical distance from services, lack of transport and lack of funds to purchase insurance (Council of Europe, 2012; Idzerda et al., 2011; Kuehlbrandt et al., 2014; McFadden et al., 2018; Rechel et al., 2009; FRA, 2018b). Fear of intrapersonal discrimination and poor past experiences of health services can also lead Roma to choose not to access services, as was reported by Roma surveyed in Slovakia (Jarcuska et al., 2013).

After Roma patients establish initial contact with health services, they may encounter segregated facilities, as well as 'hostile, patronising, judgemental, unsympathetic and even abusive attitudes of healthcare staff', leading them to feel that health professionals do not take their needs seriously (McFadden et al., 2018, pg. 78). When Roma make contact with UK health services, they face a number of practical impediments to communication with health professionals, many of which bear a direct connection to their migrant status. Barriers to adequate care may arise from limited understanding of UK health systems, difficulties in registering with GPs and inability to communicate with health professionals due to language barriers (Craig, 2011; Tobi et al., 2010). Furthermore, health services do not monitor for Roma ethnicity, which places restrictions on providers' knowledge of the ethnic and cultural backgrounds of the patient groups they serve (Greenfields, 2017; Traveller Movement, 2014). The Traveller Movement (2014) has flagged this issue, highlighting the lack of inclusion of Gypsy, Roma and Traveller ethnicities in the NHS data dictionary.

For Roma migrant communities, communication and language barriers have a significant impact on accessibility of health services, awareness of screening and immunisation programmes and overall satisfaction with services (Warwick-Booth et al., 2017). Not only are Roma frequently reliant on interpreters to communicate with healthcare practitioners, which can create barriers to the disclosure of sensitive information, but they must also communicate with interpreters in a second language due to a lack of Romanes speaking interpreters (McFadden et al., 2018). It is further worth noting that the Romanes language does not include terms for terms such as ‘depression’ and ‘anxiety attacks’, which may create barriers to accurate self-expression in mental health settings (Roma Support Group, 2012, p. 68; Darnall Wellbeing, 2018). Even amongst Roma who speak some English, low levels of education and limited literacy may contribute to difficulties in understanding medical terminology and communicating their needs to health professionals (Condon & Salmon, 2015).

Despite reports of discrimination and restricted access, however, there are also programmes that have effectively enabled Roma to access health services. Health mediator initiatives in Romania, Bulgaria and Slovakia, in which members of the Roma community actively assist their fellow Roma in establishing meaningful contact with health services, have led to increases in use of health services, vaccination uptake and patient satisfaction (European Commission, 2014; Roman et al., 2013; FRA, 2018a). Additionally, peer education programmes based on active outreach by community members have brought about increased knowledge of tobacco risks and safe sex (Carr et al., 2014).

2.3 The Roma Support Group and past work in the area of Roma health

RSG is the first Roma-led registered charity in the UK, and was established in 1998 by Roma asylum-seekers from Eastern Europe, who aimed to empower their community by facilitating their access to self-representation and information. During the last 23 years, RSG has developed models of best practice regarding the empowerment and integration of Roma communities, becoming one of the leading experts in the UK.

RSG supports thousands of Roma families to access housing, education, health and employment. In addition to frontline engagement with Roma communities, RSG has a strong track-record of delivering action research (Roma Support Group, 2011) and campaigning for greater inclusion of Roma interests in policy on national and local levels. Community consultation is at the heart of RSG’s engagement with public services, providing insights into the ways in which Roma understand their needs and informing the manner in which RSG advises professionals. In the area of health, RSG plays an instrumental role in raising the profile of Roma communities within local health services and equipping community members with the information and support they need to manage their health conditions. RSG's work on the Department of Health's Pacesetters Programme raised awareness of Roma health through community training events (Van Cleemput et al., 2010), and RSG has applied its knowledge of the health needs of Roma communities by developing and delivering a series of cultural awareness training sessions for health professionals (Roma Support Group, 2017).

RSG has undertaken in-depth work in the area of Roma mental health through its first Mental Health Advocacy Project, which ran from 2008 to 2011. This project formed the foundation of the current Project, offering insight into the prevalence of mental health issues amongst RSG service users and pointing to disproportionately high rates of depression and anxiety (see table below). Many of the initial project's beneficiaries struggled to communicate about mental health issues, in part because they lacked the vocabulary to describe relevant emotions, and in part because Roma culture stigmatises open disclosure of mental health issues. Mental illness can bring shame not only on an individual, but also on that person's entire family. As such, many Roma will avoid seeking out mental health support until their problems become so severe that they are no longer able to independently cope (Roma Support Group, 2012).

Table 1: Findings of RSG's 2008-2011 Mental Health Advocacy Project

Mental health issue	**Percentage of service users**
Organic, including symptomatic, mental disorders due to brain damage	1%
Substance-related disorders (alcohol dependency)	6%
Schizophrenia and other psychotic disorders	11%
Mood disorders	61%
Anxiety disorders	19%
Disorders, usually first diagnosed in infancy, childhood or adolescence	17%

Other mental health problems	4%

2.4 Need for the Project

Roma communities in the UK face a complex set of health inequalities – with life expectancy 10-12 years lower than population averages, and higher rates of life-limiting illness (FRA, 2012). This is rooted in discrimination against Roma in their Eastern European countries of origin and the challenges of understanding UK health systems following migration (Craig, 2011). Roma commonly find their efforts to address health needs restricted by limited access to education and difficulties in understanding communication from health professionals, as well as by cultural taboos related to health and consequent delays in accessing services (European Commission, 2014). Furthermore, language barriers, limited knowledge of UK service provision frameworks and limited awareness of Roma needs amongst service providers come together to prevent effective transmission of health information (Brown, Scullion & Martin, 2013).

RSG’s past work on mental health underpins this data and suggests higher rates of mental health issues in Roma communities compared to population averages. This work further suggests that many Roma will avoid mental health support due to cultural stigmas associated with mental health, limited awareness of available mental health services and lack of vocabulary for communicating with mental health professionals. The limited academic research conducted on mental health in UK Roma communities further indicates high rates of anxiety and depression, compounded by disproportionate barriers to accessing mental health services (McFadden et al., 2018; Tobi et al., 2010; Warwick-Booth et al., 2017). In light of these combined impediments to Roma community members’ engagement with mental health support, the Project provided culturally sensitive advocacy and informational materials to increase Roma beneficiaries’ confidence in engaging on the topic of mental health.

3. The Project

3.1 The Project team

The Project employed three part-time members of staff: a Project Coordinator working 21 hours per week and two Mental Health Advocates each working 7 hours per week. The Project Coordinator oversaw the Advocates' day-to-day contact with Project beneficiaries; conducted Project monitoring and self-evaluation; planned and facilitated peer support group meetings; developed informational materials for Roma beneficiaries and professionals; and developed and delivered the training programme for mental health professionals.

Mental Health Advocates were tasked with conducting 1-2-1 mental health advocacy sessions with Roma beneficiaries, supporting the delivery of peer support group meetings, and assisting in the delivery of training to mental health professionals.

Table 2: The Project team

Role	**Duties**
Mental Health Advocacy Project Coordinator	• Facilitating an independent one-to-one and peer mental health advocacy service for Roma refugees and migrants, and ensuring that their rights are recognised, respected and upheld • Providing line management for two Mental Health Advocates • Coordinating the work related to publishing and disseminating information about mental health issues and the mental health system

	for Roma community members - Collaborating with Mental Health professionals in order to deliver support for Roma beneficiaries and provide them with information about Roma culture
Roma Mental Health Advocate (x2)	- Conducting one-to-one mental health advocacy sessions with Roma beneficiaries, assisting with referrals to mental health services, requesting language support for medical appointments and communicating with service providers about beneficiaries' cultural backgrounds - Assisting with the delivery of monthly peer support group meetings - Disseminating information about mental health issues within the Roma community - Supporting the Project Coordinator in delivering training sessions for health professionals

The Project Coordinator provided floating supervision and support throughout the Mental Health Advocates' working days. The Project team met weekly to discuss complex cases and plan future Project activities. All team members received supervision from the RSG CEO on a six-weekly basis.

Furthermore, the Project engaged eight volunteers, who assisted with the project reception duties; language support; compiling a database of mental health services in the Project's key areas of operation; gathering follow-up feedback from professionals who engaged in training sessions; and developing informational materials for Roma beneficiaries. Their duties also included collecting Distance Travelled Forms (DTF) from beneficiaries and developing digital content for our Facebook page. We recognised the importance of recruiting experts by experience, i.e., volunteers with lived experience of mental health difficulties and recovery.

3.2 Involvement of other RSG projects

The Project worked closely with other RSG projects, most notably the Roma Advocacy Project, the Housing Advocacy Project and the Aspiration Project (which provided education support). Other projects also referred beneficiaries struggling with mental health issues to the Project. Additionally, the Project referred beneficiaries to other projects when sessions brought up issues around welfare support, housing insecurity and difficulties in accessing education.

The most in-depth inter-project collaboration occurred with the Advice & Advocacy Project, through which the Project provided substantial health-related welfare assistance to beneficiaries, ensuring that the beneficiaries continued to receive holistic support whilst the Project team focused on mental health advocacy work.

However, during the COVID-19 crisis, the impact of financial and housing problems on mental health became exacerbated, so we began to work more closely with our Financial Inclusion Project. We co-facilitated sessions on the link between finance/housing and mental health problems and co-delivered a peer support group focussing on this intersection. In addition, we recognised that with Brexit, there was an increase in anxiety levels related to our beneficiaries' immigration status. We collaborated with our EUSS Project, co-delivering sessions that addressed these issues.

3.3 Key stakeholders

The Project maintained close working relationships with East London Foundation Trust, North East London Foundation Trust, Newham CCG, Waltham Forest Talking Therapies, Healthwatch Newham, Mind in Tower Hamlets and Newham, and Redbridge CVS. These stakeholders assisted with disseminating information about Project activities and recommended services for participation in the Project's Roma Cultural Awareness training. In particular, the People Participation Lead at East London Foundation Trust was instrumental in arranging the delivery of short presentations from health professionals at the Project's peer support group meetings.

Agencies, such as Alzheimer's Society, Change, Grow, CAMHS (Children and Adolescents MH service in Newham), North East Foundation Trust (NELFT), Redbridge Council for Voluntary Services (CVS); Kent NHS and Newham Council have assisted in identifying professionals to deliver awareness sessions on beneficiaries' areas of concern. In addition, Newham, Barking and Dagenham and Havering and Redbridge CCGs were instrumental in helping us to promote our training sessions for health professionals.

3.4 Service users – numbers and characteristics

In the Project's five years, the team assisted a total of 753 distinct beneficiaries over the course of 1,845 advocacy sessions. This equates to:

- 141 beneficiaries assisted in Year 1 over the course of 268 advocacy sessions
- 185 beneficiaries assisted in Year 2 over the course of 543 advocacy sessions
- 136 beneficiaries assisted in Year 3 over the course of 392 advocacy sessions
- 162 beneficiaries assisted in Year 4 over the course of 310 advocacy sessions
- 220 beneficiaries assisted in Year 5 over the course of 332 advocacy sessions

The Project delivered 53 peer support group meetings over its five years in operation, reaching a total of 66 distinct beneficiaries. This equates to:

- 10 peer support group meetings in Year 1 attended by 27 distinct beneficiaries
- 11 peer support group meetings in Year 2 attended by 35 distinct beneficiaries
- 11 peer support group meetings in Year 3 attended by 32 distinct beneficiaries
- 10 peer support group meetings in Year 4 attended by 34 distinct beneficiaries
- 11 peer support group meetings in Year 5 attended by 31 distinct beneficiaries

Table 3: Gender of beneficiaries

	Year 1	Year 2	Year 3	Year 4	Year 5
Male	42%	30%	32%	40%	37%
Female	58%	47%	68%	60%	63%
Transgender	0%	0%	0%	0%	0%
Not stated/no data	0%	23%	0%	0%	0%

Table 4: Age of beneficiaries

	Year 1	Year 2	Year 3	Year 4	Year 5
0-15	2%	2%	3%	2%	1%
16-24	6%	6%	7%	6%	5%
25-44	30%	21%	32%	38%	40%
45-64	45%	42%	52%	39%	43%
65-74	6%	6%	6%	5%	4%
75 and over	0%	0%	0%	0%	0%
No data	11%	23%	0%	10%	7%

Table 5: Mental health profile of beneficiaries

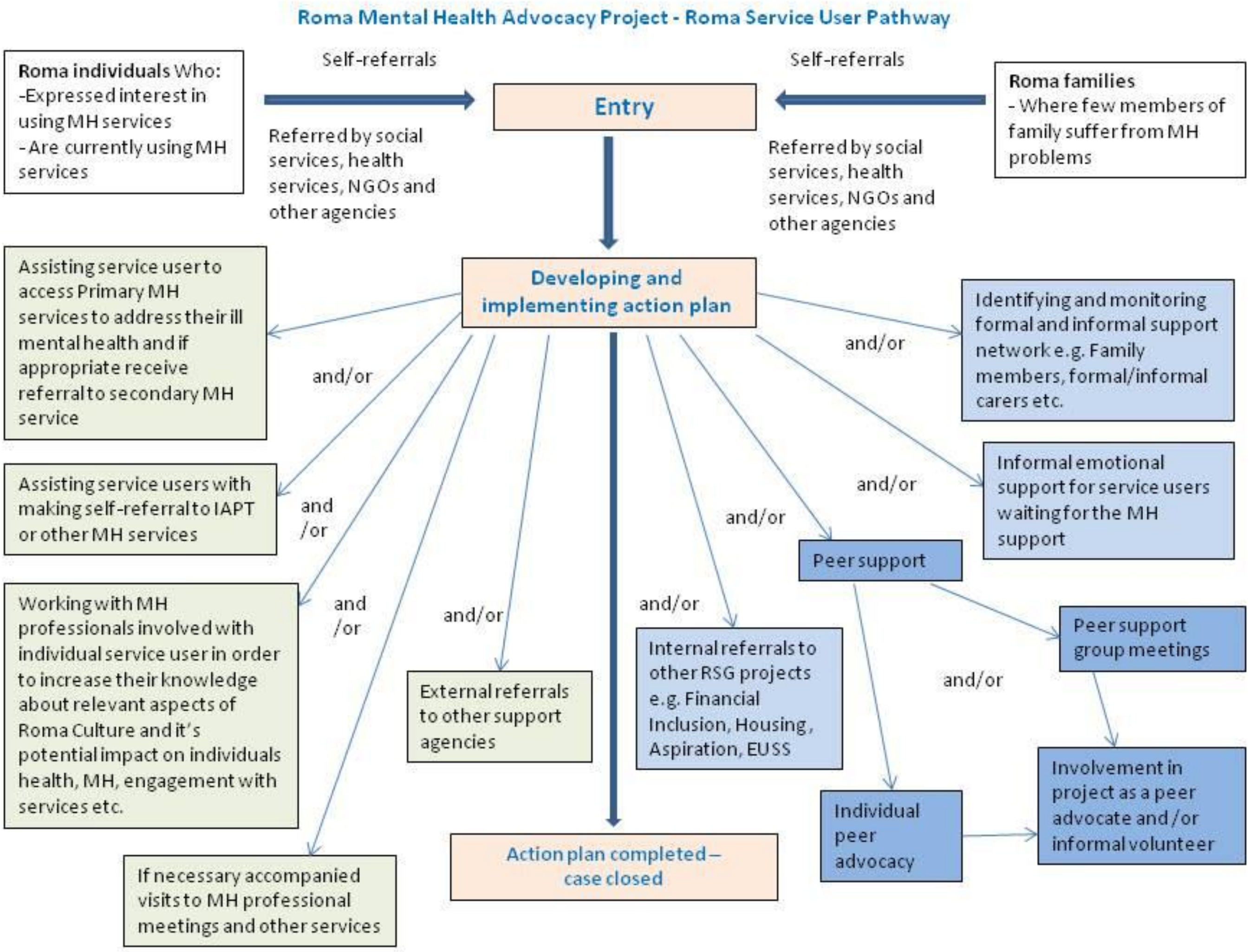
Mental health issue	Percentage of beneficiaries
Depression	69%
Anxiety	30%
Panic attacks	16%
Schizophrenia	12%
Substance Misuse	8%
Psychosis	8%
Autism and other developmental disorders	8%
Hallucinations	8%
Post-traumatic stress disorder	3%
Obsessive compulsive disorder	1%
Anger management issues	1%

*Please note, some of the beneficiaries are included in more than one category.

3.5 Project activities

In figure 1 below, the user Pathway illustrates different ways our beneficiaries could access the Mental Health Project, different types of support offered including accessing and navigating mental health services, participating in peer support groups and other activities.

Figure 1: User Pathway



3.5.1 Facilitating access to mental health services

During 1-2-1 advocacy sessions, the Project team supported beneficiaries to complete self-referral forms for mental health services, or wrote to GPs and assessment teams with requests for referrals. In the first year, there was a rush of beneficiaries approaching the team with specific requests for referrals to mental health services. These beneficiaries had accessed RSG's previous mental health project and thus were already familiar with mental health services and referral mechanisms. In the Project's latter years, activities shifted to focus on assisting beneficiaries to sustain contact with mental health services and supporting them to obtain re-referrals after the completion of a course of therapy.

During the Project's lifespan, we have made 111 referrals to mental health services as well as receiving referrals from external agencies, which have significantly increased in the final year of the Project. These included referrals from Social Services from Islington, Newham, Thurrock and Warrington; Learning Disability Services; Adults in Transition and Urgent Response Team; Triangulate Social Care Solutions, Hibiscus, etc.

Table 6: Referrals to mental health services (including assistance with self-referrals)

Service	***Percentage of service users referred to the specified service**
Newham Talking Therapies (IAPT)	30.75%
Newham Assessment and Brief Treatment Team	14.7%
Newham Child and Adolescent Mental Health Service (CAMHS) Waltham Forest Talking Therapies	7.85%
NELFT Secondary Mental Health Services	6.25%
Back on Track (IAPT) Hammersmith and Fulham	5.7%
Newham Occupational Therapy	5%
Newham Physiotherapy	5%
Newham Child and Adolescent Mental Health	3.8%

Service (CAMHS)	
WLMHT Single Point of Access	3.8%
CAMHS Newham	3.8%
IAPT Enfield	3.8%
Hammersmith and Fulham Single Point of Access	3.8%
Waltham Forest Talking Therapies	3.75%
Traumatic Stress Clinic	2.5%
ELFT Diagnostic Memory Clinic	2.5%
IAPT Southend	1.9%
Therapy for You in Southend	1.9%
Waltham Forest Access, Assessment and Brief Intervention Team	1.9%
Brent Talking Therapies	1.9%
Mind Bereavement Service in Newham	1.9%
Redbridge Access, Assessment and Brief Intervention Team	1.9%
Emotional Wellbeing and Mental Health Service Redbridge	1.9%
Redbridge Learning Disability Team	1.9%
Enabling Assessment Service London	1.9%
Futures East Mentoring Programme	1.9%
Change, Grow, Live Newham	1.9%
British Deaf Association	1.9%
Hestia	1.9%
Maggie’s	1.9%
Refuge	1.9%
Family Rights Group	1.9%
Speech Therapy Service	1.9%
Audiology	1.25%
Autism specialist dental services	1.25%

IAPT Barking and Dagenham	1.25%
IAPT Camden and Islington	1.25%
IAPT Croydon	1.25%
Hackney Family Therapy	1.25%
IAPT Hammersmith and Fulham	1.25%
IAPT Haringey	1.25%
Newham Children’s Occupational Therapy	1.25%
Newham Community Mental Health Team	1.25%
Newham Recovery Team South	1.25%
Newham Social Services	1.25%
Waltham Forest Children’s Physiotherapy	1.25%

*Please note, some of the service users were referred to multiple services.

Case study

B. is a 30-year-old man who has depression and auditory hallucinations. He struggled with mental illness for many years but had never accessed any treatment and felt that he was reaching a crisis point. Since he required access to secondary mental health services, the Project team assisted him with booking a mental health assessment with the GP.

To facilitate a suitable referral, the Project sent a supporting letter further explaining his problems and attached information leaflets about Roma culture and attitudes to health.
The GP utilised the information included in our leaflet and letter, and ensured that the questions were asked slowly and that the patient understood each and every question and was explained in detail the referral process to mental health service.

B. contacted us after the assessment and reported being pleased with how the assessment was conducted and that he felt understood.

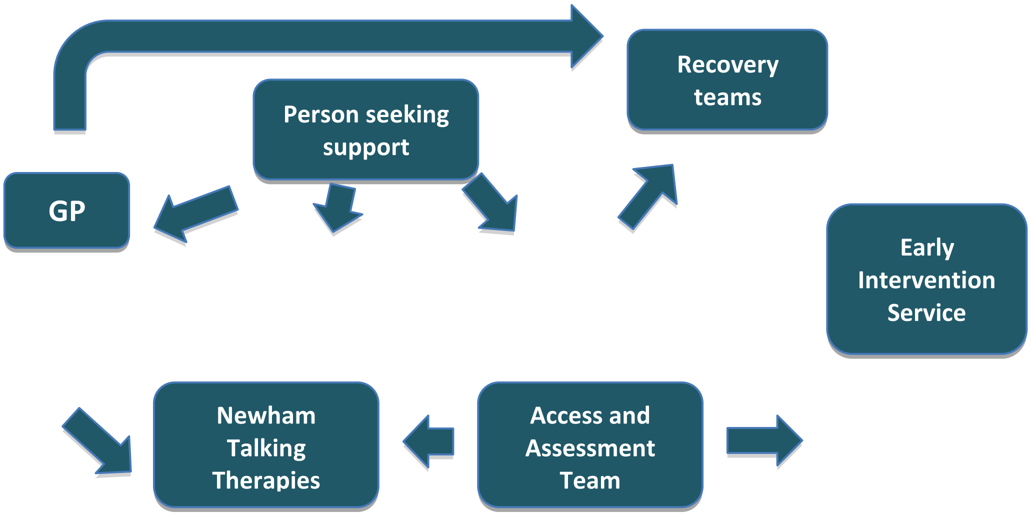
3.5.2 Assisting with navigation of mental health services

The initial activities of the Project focused on referrals to talking therapy services, as these offered self-referral mechanisms and allowed beneficiaries to obtain a relatively rapid resolution to their concerns. After making a number of referrals of this type, however, it became clear that many beneficiaries were struggling to complete the initial telephone assessment for entry into the service. To remedy this issue, the Project began to make referrals to local access and assessment teams which served as a ‘single point of contact’ with all mental health services. It also offered assessment mechanisms that were more tailored to beneficiaries’ language and communication support needs. Although this approach generally resulted in a referral to talking therapy, it ensured that beneficiaries’ language support needs were addressed at the point of assessment and that continuity of language support was offered throughout beneficiaries’ contact with mental health services.

The Project staff have spent significant time providing information on different mental health conditions and treatments available, and supporting service users with limited ability to express emotion during their mental health assessments. We have worked with individuals, as well as whole families and have recognized the intergenerational trend of susceptibility to mental illnesses. This in turn, helped us to further identify possible beneficiaries, which resulted in multiple referrals to primary mental health services and assistance in accessing secondary mental health services.

During the pandemic some of our clients, who either did not have access to the internet and suitable devices, or were unable to use it, faced digital exclusion. Additionally, with the statutory mental health services already stretched, there was an increase in demand and severity of new referrals during lockdown, thus many people failed to get ~~the~~ support. We ensured that regular telephone follow ups were being done by the Project team and emotional support was being offered to these clients.

Figure 2: Typical referral pathways in L.B. Newham



The referral pathway is the same for all London boroughs – we were only able to refer clients to IAPT or Access and Assessment Teams/ Single Point of Access. If clients' problems were severe and they required secondary/specialised mental health services – we would book an assessment with the GP and send a supporting letter/email stating their problems, needs and limited capacity for expressing their difficulties. Occasionally we would also attend an assessment with the client.

3.5.3 Peer support group meetings

Over the course of the Project, the structure of peer support meetings has progressed through a number of changes. The initial meetings were structured around raising general awareness of mental health issues, yet as group participants' understanding of mental health increased, the meetings developed into an open forum for learning from one another and co-planning future project activities. As the Project moved into its second year, beneficiaries increasingly expressed an interest to incorporate in the meetings direct input from mental health professionals on the support offers available through various local mental health services. The Project Coordinator thus liaised with local health service providers to arrange times for them to visit the RSG office and deliver short awareness sessions to peer support group participants which focused on treatments, support available and coping strategies.

Beneficiaries were offered a space for group discussion, sharing their struggles and ways of managing them. This in turn, enhanced their sense of self-empowerment and increased their confidence in making positive choices related to their mental health (as reported by the beneficiaries in their feedback forms). Moreover, these sessions offered an opportunity for building trust between our service users and health professionals, which in turn enhanced their confidence to engage with mental health services. In the final year of the Project, peer support activities shifted towards sessions aimed at preparing beneficiaries to independently access services and cope with mental health issues.

Peer Support Meeting topics included:

- Depression awareness
- Anxiety awareness
- Children's mental health
- Dementia awareness
- Mindfulness
- Coping mechanisms
- Housing insecurity and its impacts on mental health
- Immigration insecurity and impacts on mental health
- Mental health service mapping exercises

Beneficiaries attending peer support group meetings reported their positive impact in helping them to learn more about mental health with other members of the community:

> *'I attend focus groups, support groups and learn about my mental health.'*

Further feedback from beneficiaries suggested that peer support group meetings not only increased knowledge of mental health issues, but may also have sparked more open communication about mental health within the Roma community:

> *'[It is helpful] to be able to share experiences about mental problems with other Roma people.'*

During the pandemic we continued to offer peer support group meetings digitally, via Zoom. This offered a space to meet with other community members and professionals, discuss their fears and concerns, and exchange coping strategies, which in turn, helped to strengthen trust between our beneficiaries and health professionals. In addition, they were assisted in developing new skills related to accessing digital appointments, which increased their independence in maintaining engagement with health services.

'At first I did not have much understanding of mental health. Attending peer support groups enabled me to see that my depression was a common problem in our community and I have learnt different strategies to deal with negative thoughts that I was having.'

Case studies: Learning through peer support

Case study 1

In the Project's second year, beneficiaries began to approach the team with concerns about changes in their aging parents' memory and behaviour. While referrals to diagnostic memory clinics were helpful in individual cases, it became clear that there was demand for wider awareness raising on the topic of dementia. The team contacted the Alzheimer's Society with a request for assistance in delivering a peer support session, and one of its outreach workers came to the RSG office to deliver a session on dementia awareness.

After receiving support from the Project and the Alzheimer's Society to secure a referral to the local diagnostic memory clinic, the beneficiary commented: *'I asked my GP for a dementia assessment for my mother, but he wouldn't make the referral. It was only with help from the Project team that she finally was referred for assessment. Now that we know she has early onset dementia, we know how to care for her.'*

Case study 2:

In the fourth year of the Project, the staff have been approached by multiple women suffering from fibromyalgia, feeling frustrated over lack of understanding of their diagnoses and lack of available treatment. It became clear that there was a demand for a group session with a specialist, which would allow them to share their struggles and experiences. The Project Coordinator was able to arrange a session facilitated by a Self-Care Facilitator from NELFT.

The session allowed our beneficiaries to learn about current research, the causal associations and techniques that help ease the pain. During the session, one client shared that she had never had an opportunity to meet someone else with similar experiences and had struggled in silence for years as she did not want to be a burden for her family. The session gave her a long-awaited space to discuss her experiences, learn more about the illness and practice exercise reflecting the power that the mind holds in influencing physiological responses. The session also offered information about the local support groups for fibromyalgia-sufferers.

After receiving support from the Project and NELFT to secure a referral to the local support group, the beneficiary commented: *'I have suffered from this illness for years and was never given any information about the support available. The Project team enabled me to finally share my experiences and learn so much in just one session. I was also able to access further support in the community. I am finally able to implement techniques that help ease the pain.'*

Case study 3:

During the pandemic we have seen an increase in people struggling with mental health issues. The Project team was approached by multiple clients enduring a sense of loss, loneliness and isolation, and many beneficiaries' pre-existing conditions worsened during the lockdowns. The need for space where people could meet digitally and share their struggles had never been greater.

One beneficiary, who struggled with severe mental health problems, developed suicidal thoughts during the pandemic. We ensured that she was offered regular telephone check-ups with our staff and continually liaised with her psychiatric team. We decided to organise a peer support group to offer additional support to people who struggled during the lockdown. This allowed an opportunity for discussing the worry cycle, how people worry about things that are out of their control. The beneficiaries shared their fears about their families getting infected and how this impacted on their mood, behaviour and physical symptoms. They also shared feelings of isolation and depression. We discussed ways to talk oneself out of unhelpful thinking and over-worrying, i.e., focusing on things that are within our control, noticing the unhelpful thoughts and distracting oneself with pleasurable activity.

3.5.4 Development of leaflets for Roma community members

The Project developed leaflets for Roma community members based on consistent feedback from beneficiaries. The first text-based draft of the leaflet was presented at a peer support group meeting, in which beneficiaries pointed out that the format would be inaccessible to community members with limited literacy. Taking this into account, the next version of the leaflet was image-based and offered a basic outline of the support available through the Project.

While the image-based leaflet was effective to direct Roma beneficiaries towards Project services, questions continued to arise during peer support group meetings (e.g.: 'What is mental health?'; 'What mental health services are available?'; 'Is it possible to cure mental health issues?') that suggested the need for a more detailed leaflet about mental health issues. Responding to this feedback, the Project team updated the leaflet to incorporate a simple graphic format that conveys basic information about common mental health issues and ways to access relevant services.

Leaflet distribution progressed as follows:

- 105 leaflets distributed in Year 1
- 100 leaflets distributed in Year 2
- 100 leaflets distributed in Year 3
- 150 leaflets distributed in Year 4
- 140 leaflets distributed in Year 5 + approx. 2500 viewed our digital content on Facebook

In the last year of the Project, approx. 140 leaflets have been disseminated to our beneficiaries digitally, via email, WhatsApp and Facebook. In addition, we regularly produced online content through our website and social media channels (e.g., Facebook) in different community languages. It included up-to-date information about COVID-19, Government guidelines and mental health during pandemic, making this information accessible to thousands of Roma across the UK. At least 500 people on Facebook viewed our posts and approximately 2,000 viewed our videos.

3.5.5 Engagement with mental health professionals

The Project engaged mental health professionals and GPs through a combination of direct support, Roma cultural awareness training sessions and informational leaflets outlining key mental health concerns for Roma community members.

Support for professionals proceeded accordingly:

- Year 1: 31 professionals directly supported; 133 attended training sessions; 164 leaflets distributed
- Year 2: 34 professionals directly supported; 95 attended training sessions; 132 leaflets distributed
- Year 3: 58 professionals directly supported; 27 attended training sessions; 85 leaflets distributed

- Year 4: 55 professionals directly supported; 75 attended training sessions; 150 leaflets distributed
- Year 5: 68 professionals directly supported; 59 attended training sessions; 160 leaflets distributed

Years 1 and 2 saw high levels of engagement in the professional training sessions, as a result of the Project's participation in a Newham CCG-sponsored programme for delivering short Roma Culture Awareness sessions to local GP practices and mental health services. These sessions were delivered in-house and lasted on average between 30 minutes and 1.5 hours. This training structure allowed for intensive engagement with health professionals, yet the short length of the sessions also limited the depth of information conveyed. In Years 3-5, the Project delivered two day-long, in-depth sessions to a smaller number of professionals.

Professionals who attended training sessions and received leaflets uniformly reported that they expanded their knowledge of Roma health and culture, and in some cases provided them with actionable tips for adjusting their practice to better serve Roma patients. One member of a GP practice's staff commented:

> *'It was an eye-opener for us to know that there are different sections in the Roma community…They have different dialect as well. We, as health professionals, might be mixed up with it. People might not say they are Roma; they might say they're Polish, Romanian or Slovak. [The training] gave a clear idea about the community and how health services around them could support them.'*

Other professionals attending in-house sessions in GP practices and mental health services reflected on the gains in knowledge resulting from the training, and the ways in which this increased knowledge would influence their future practice:

> *'This [training] has changed my perception and boosted my confidence to work effectively with this community.'*

Professionals further described how they would communicate the lessons learned during training to their teams, thus improving engagement with Roma patients across the service:

> *'I will share the information I have learned with my team. I will contact you for help working with Roma service users in the future if needed. I am aware of barriers to engagement and will try to negotiate these.'*
> *'I intend to feedback to my team to create more awareness about cultural aspects and barriers among Roma community.'*

In Year 4, the Project Coordinator focused on establishing new collaborations with external agencies, including local charities and statutory services, such as Alzheimer's Society, CGL, CAMHS, IAPT, Access and Brief Treatment teams and Recovery Teams across different London boroughs, including Hackney, Newham, Waltham Forest, Barking and Dagenham and Hammersmith and Fulham. Additionally, we engaged with multiple professionals in training seminars and worked with East London Foundation Trust and Healthwatch Newham to promote improvements in service delivery to Roma patients.

In Year 5, we focused on sustaining existing collaborations and creating new partnerships across the mental health sector. We saw an increase in referrals from external organisations and a higher need for a multi-agency work. We were able to support multiple professionals in their work with Roma, and collaborated with ThriveLDN through gathering feedback on mental health service provision during the pandemic and offering suggestions for improvements.

Throughout the Project, we were able to gather positive feedback from professionals who attended our training sessions, outlining the improvement in their understanding of Roma culture, barriers to access and engagement:
'The online training was really informative and gave lots of detailed information about barriers to engaging with Roma people and practical advice of how best to seek to engage with Roma people, which is really helpful in supporting building links with this diverse community.'

'Excellent training! … It gave me the knowledge of Roma culture and how to approach, communicate and support them. The leaflet is also very helpful as I can always go back to the information.'

Presentation for health professionals delivered at the health conference in February 2020

4. Self-evaluation methods

4.1 Data collection: Tools and methods

The Project employed three main data collection tools: Distance Travelled Forms (DTFs), satisfaction surveys and feedback forms. DTFs tracked a cohort of beneficiaries' self-reported progress in six-month intervals across key outcome areas:

1. Roma beneficiaries have improved access to mental health services.
2. Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available.
3. Roma beneficiaries have increased level of satisfaction with mental health services.
4. Roma beneficiaries with mental health issues report improved wellbeing.
5. Mental health service providers have increased awareness of Roma patients' needs.

A different cohort of approximately 20 beneficiaries was selected for DTF monitoring for each year of the Project, to achieve a representative sample of beneficiaries across the Project's five years.

Where DTFs measured change over time, satisfaction surveys provided insight into beneficiaries' immediate impressions of mental health services. Any beneficiary who had accessed mental health services would be asked to complete a satisfaction survey (whereas DTFs monitored only a selected cohort of beneficiaries).

Feedback forms then measured beneficiaries' satisfaction with the assistance and support provided by the Project team and offered opportunities to suggest improvements to the Project.

To supplement the monitoring forms, the Project team kept detailed case records, conducted informal interviews with Roma beneficiaries and recorded minutes from peer support group meetings. The Project furthermore maintained a detailed database of beneficiaries, recording the gender, age, location of residence, number and type of referrals to mental health services, key health issues and methods of referral into the Project. This qualitative data added depth to the quantitative findings and, if progress toward outcomes fell below target, offered explanations as to the reasons for beneficiaries' dissatisfaction with service accessibility and interactions with mental health professionals.

Table 7: Data collection methods

Method	**Associated Project activities**	**Outcomes measured**
Distance Travelled Forms	1-2-1 advocacy sessions	Roma beneficiaries have improved access to mental health services Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available

		Roma beneficiaries have increased levels of satisfaction with mental health services Roma beneficiaries with mental health issues report improved wellbeing
Satisfaction surveys	1-2-1 advocacy sessions	Roma beneficiaries have increased levels of satisfaction with mental health services
Feedback forms	1-2-1 advocacy sessions Peer support group meetings Production of a leaflet for Roma community members	Roma beneficiaries have improved access to mental health services
Case records	1-2-1 advocacy sessions	Roma beneficiaries have improved access to mental health services Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available Roma beneficiaries have increased levels of satisfaction with mental health services Roma beneficiaries with mental health issues report improved wellbeing
Informal interviews	1-2-1 advocacy sessions	Roma beneficiaries have improved access to mental health services Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available Roma beneficiaries have increased levels of satisfaction with mental health services

		Roma beneficiaries with mental health issues report improved wellbeing
Peer support meeting minutes	Peer support group meetings	Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available Roma beneficiaries with mental health issues report improved wellbeing
Feedback forms from professionals	Training seminars for health professionals	Mental health service providers have increased awareness of Roma culture and Roma patients' specific needs
Follow-up emails/phone calls with professionals	Direct support and advice for health professionals Production of a leaflet for health professionals	Mental health service providers have increased awareness of Roma culture and Roma patients' specific needs

4.2 Sampling

Regular users of Project services were selected for DTF monitoring, with a different cohort of approximately 20 beneficiaries participating in DTF monitoring for each of the Project's five years.

Satisfaction surveys were gathered from beneficiaries during follow-up advocacy sessions after referrals to mental health services. This survey data aimed to capture the impressions of all beneficiaries whom the Project had referred to mental health services.

Feedback forms were gathered quarterly from approximately 10 beneficiaries per quarter, capturing roughly equal numbers of long-term and new users of the Project in each round of feedback monitoring.

4.3 Methods of data analysis

DTF questions asked beneficiaries to assign numerical ratings to their levels of access to mental health services, understanding of mental health issues, satisfaction with mental health services, sense of overall wellbeing and impressions of mental health professionals' understanding of the Roma community and culture. Each DTF was first assessed for whether the beneficiary reported an increase, decrease or no change across each outcome area. The total number of increase, decrease and no change responses were tallied for each outcome, and divided by the total number of beneficiaries to calculate the overall progress towards each outcome.

DTF forms were constructed so that beneficiaries reported responses on a 1-10 scale, thus allowing for easy calculation of percentage change for each outcome area. In this sense, a 2-point increase in a beneficiary's self-reported progress on an outcome would represent a 20% increase for that outcome area. Average percentage changes were calculated for each outcome. DTFs were collected every six months from a key cohort of beneficiaries (with a different cohort selected for each of the Project's years) to record 'distance travelled' across four outcome areas (the fifth outcome area focuses on health professionals, and was measured according to different monitoring tools).

Analysis of satisfaction surveys and feedback forms involved calculation of response percentages for each question. Answers to open-ended questions were entered into a database and analysed qualitatively to identify recurring themes.

Qualitative data, including case records, informal interview notes and peer support group meeting minutes, was entered into the Project's online database and analysed for key themes.

5. Results

5.1 Project impact in improving access to mental health services:

5.1.1 Achieving Outcome 1: "Roma beneficiaries have improved access to mental health services."

The Project supported beneficiaries to make and maintain contact with mental health services through facilitating initial referrals (either by making a direct referral or contacting beneficiaries' GPs with referral requests), accompanying vulnerable beneficiaries to appointments and providing health professionals with informational materials about mental health communication in Roma communities. These measures sought to counter barriers to mental health services stemming from language barriers, complex referral mechanisms and fear of seeking out mental health support.

Case records revealed that progress towards improving access to mental health services occurred not only through assistance with self-referrals and requests to professionals for referral, but also through activities that helped them to understand mental health systems and overcome their fears related to mental health services. This served as a vital first step in facilitating access to mental health services. The Project supported 141 beneficiaries in Year 1, 185 beneficiaries in Year 2, 136 beneficiaries in Year 3, 162 beneficiaries in Year 4 and 220 beneficiaries in Year 5, to increase their understanding of what services are available and to communicate more effectively with GPs about mental health. Additional Project activities, such as ensuring provision of language support, booking GP appointments, registering with GP practices, accompanying beneficiaries to hospital appointments, and in the final year, teaching digital skills, further facilitated greater ease of access to mental health services.

Feedback from beneficiaries emphasised the positive impacts not only of referrals to mental health services (and assistance with self-referrals), but also of the Project's holistic approach to mental health support. For some, these improvements were achieved through the Project's work in directly facilitating access. For others, a combination of direct referrals to mental health services and support with general health, housing and welfare issues was key to increasing beneficiaries' confidence in using mental health services:

> *'I was referred to talking therapies. Also, I am supported by mental health team worker. They provide floating support, which is very important as I do not have to attend office appointments, which is very difficult due to complex health problems.'*

Ultimately, the Project's work in heightening service accessibility was vital in building beneficiaries' overall confidence:

> *'Thanks to the team for helping me become more comfortable with my mental health. Our community needs more people like them helping us.'*

During the COVID-19 crisis, the Project Coordinator met with external organisations, including ThriveLDN and Healthwatch Newham, to address how the pandemic was affecting Roma people's experiences with health services. Suggestions were provided for improvements regarding accessibility (language, digital exclusion), measures mitigating inequality, addressing gaps in mental health provision and utilising community assets for delivery of engagement activities. The suggestions were based on the verbal feedback from beneficiaries collected prior to the meeting. The professionals shared that:

'The feedback was very useful. There seems to be a lot of overlap in people's experiences of health services during pandemic, while simultaneously certain issues that Roma faced were new to us. Our aim is to implement changes as a result of the feedback.'

In terms of the Project's direct support in securing referrals to mental health services, progress was tracked yearly through records of the total number of referrals made to mental health services and DTF monitoring of beneficiaries' impressions of service accessibility. Annually, the Project made progress as follows:

- Year 1: The Project made 32 new referrals to mental health services; 43% of beneficiaries monitored through DTFs reported increased ease of access
- Year 2: The Project made 16 new referrals to mental health services; 61% of beneficiaries monitored through DTFs reported increased ease of access
- Year 3: The Project made 10 new referrals to mental health services; 71% of beneficiaries monitored through DTFs reported increased ease of access
- Year 4: The Project made 30 new referrals to mental health services; 45% of beneficiaries monitored through DTFs reported increased ease of access

- Year 5: The Project made 23 new referrals to mental health services; 45% of beneficiaries monitored through DTFs reported increased ease of access

5.1.2 Synthesis

The Project served as a key enabling factor in beneficiaries' access to mental health services, helping them to overcome the barriers to contact mental health services. As one beneficiary described, the decision to seek out support often required an adjustment in thinking about mental health:

> *'At the beginning I was afraid to reach out for help. I was afraid of going to a psychologist and talking about my problem. On top of that I was afraid what will other people say about me having a mental health issue. After attending few meetings at the Roma Support Group in regards to having anxiety and depression I realised that I need to reach out for help. Thanks to your support, after years of struggling and battling with my depression, I finally received professional help. I was referred to a talking therapy and it seems to work.'*

Once this contact had been established, beneficiaries commented that it was much easier to continue to engage with services. One beneficiary described how it was only with the Project's support that she was able to access mental health services and ultimately build a productive and lasting relationship with her psychologist:

> *'Therapy helped me a lot. I have more faith in myself and I feel more confident. I had a very good relationship with the psychologist and I feel safe because if something will happen to my mental health, I know where to get help.'*

In Year 4 and 5, the Project team experienced difficulties in improving accessibility to mental health services. Whilst we supported beneficiaries with new referrals to mental health services, the structural flaws within the NHS, long waiting lists and high entry criteria for primary mental health services resulted in 27% of our referrals not being accepted. This inevitably influenced beneficiaries' trust in services and willingness to access them. In Year 5, the pandemic affected mental health services' accessibility. Many of our beneficiaries, who either did not have access to the internet and digital devices, or were unable to use them, faced digital exclusion. Some of them also faced more difficulty with booking interpreters for their online appointments. Additionally, with the statutory mental health services already stretched, there was an increase in demand and severity of new referrals during lockdown, thus many people failed to get support.

Amongst beneficiaries reporting decreased ease of access to services, informal interviews revealed that unfavourable impressions of service accessibility stem from long waiting times for an initial appointment, difficulties in obtaining referrals to secondary mental health services and lack of language support during assessments. Beneficiaries reported difficulties in sustaining continuity of access to mental health services. This was a particular issue in the area of talking therapy, in which patients can receive a maximum of 20 sessions, after which they need to be re-referred. In light of many beneficiaries' reported issues with establishing trust with mental health professionals, these relatively brief courses of therapy create barriers to open engagement.

The basic operational structure of talking therapies can furthermore create barriers in light of Roma beneficiaries' cultural and communication profiles. As mental health issues have traditionally been stigmatised in Roma culture, many beneficiaries were not accustomed to talking about mental health and thus found it difficult to engage with therapists. Others lacked the vocabulary for describing certain emotions and could feel pressurised in an environment where they were expected to discuss the details of their emotional state.

Case study 1

E. is a 22-year-old woman with stage 4 colon cancer, diagnosed when she was 20. She contacted us during the pandemic as she struggled with depression and anxiety related to her health. She had previously accessed counselling via Macmillan but had a negative experience which affected her trust in therapy. We discussed different options for support such as group and individual therapy, different therapeutic modalities offered in statutory and charity services. We worked on re-building her trust in services through arranging one-to-one meeting with a psychologist from Maggies, a charity organisation providing free cancer and psychological support. Subsequently, she made the decision to access counselling via Maggies and the Project staff supported her with the referral. E. has been attending therapy for a couple of weeks, and has shared that it has been vital in re-building her trust in services and learning how to cope.

Case study 2: Accessing mental health services in a time of crisis

D. is a 14-year-old Polish Roma boy, whose mother is terminally ill and whose father is a recovering alcoholic with a range of complex health conditions. Not only was he contending with these stressors at home, but he was also the target of bullying at school. With no close friends and a limited social support network, he had no outlet for venting his fears about his mother's health and frustrations in his everyday life.

This first warning signs of severe mental distress arose when D. spent a day hiding in a park, convinced that a man was following him with the intention of doing him physical harm. From that point on his symptoms intensified. He would pound on the walls of his home, leaving indentations in the plaster, and at other times he would sink to the floor and scream for God to take him away. He threatened to jump from the balcony of his family's sixth-floor flat.

D's mother made contact with the Project team, which took rapid action to prevent further deterioration of his mental state. The team liaised with a Safeguarding Lead at his school and made contact with a psychologist at the local Child and Adolescent Mental Health Service (CAMHS), who was able to offer him an emergency assessment and agreed on a plan for regular follow-up appointments. Over the course of his engagement with mental health services, D. disclosed that he had been abusing inhalants and he received a further referral to the CAMHS substance misuse team.

The Project team assisted D. in his engagement with mental health services, accompanying him to his initial assessment and reminding him of all subsequent appointments, ensuring his continued engagement and satisfaction with the service. The team was in regular contact with his school to keep track of his day-to-day emotional state and to identify any further areas where support may be required. As D's isolation at school posed a challenge to his recovery, Project team members began to assist him beyond his direct contact with mental health services. The team helped him to participate in a programme of social activities coordinated by RSG's Aspiration Project, thus offering him a reprieve from the pressures of his everyday life.

By carrying out a targeted intervention at a time of crisis and utilising the Project's network of professional contacts to facilitate rapid access to mental health services, the Project's involvement in D's case prevented him from engaging in acts of further self-harm.
His mother commented: '*I was terrified that I was losing my son and felt totally powerless. His father also could not help him ... You have done more for my son that we were able to do. You gave him and all of us hope.'*

5.2 Project impact in improving understanding of mental health issues

5.2.1 Achieving Outcome 2: "Roma beneficiaries have greater understanding of mental health issues, as well as mental health care support and services available."

The Project raised awareness of mental health issues through 1-2-1 advocacy sessions, peer support group meetings and informational leaflets.
Progress was tracked through casework records, peer support group meeting minutes, informal interviews with beneficiaries and DTF monitoring of beneficiaries' self-reported understanding of mental health issues. Annually, the Project made progress as follows:

- Year 1: The Project engaged 141 beneficiaries in 1-2-1 advocacy sessions, 27 in peer support group meetings and distributed 105 information leaflets to the community; 71% of beneficiaries monitored through DTFs reported increased understanding of mental health issues
- Year 2: The Project engaged 185 beneficiaries in 1-2-1 advocacy sessions, 35 in peer support group meetings and distributed 100 information leaflets to the community; 78% of beneficiaries monitored through DTFs reported increased understanding of mental health issues
- Year 3: The Project engaged 136 beneficiaries in 1-2-1 advocacy sessions, 32 in peer support group meeting and distributed 100 information leaflets to the community; 86% of beneficiaries monitored through DTFs reported increased understanding of mental health issues.

- Year 4: The Project engaged 162 beneficiaries in 1-2-1 advocacy sessions, 34 in peer support group meetings and distributed 130 information leaflets to the community; 75% of beneficiaries monitored through DTFs reported increased understanding of mental health issues
- Year 5: The Project engaged 220 beneficiaries in 1-2-1 advocacy sessions, 31 in peer support group meetings and distributed 140 information leaflets to the community; 80% of beneficiaries monitored through DTFs reported increased understanding of mental health issues

Peer support groups helped with challenging stigma in the community through normalising mental illness, challenging shame surrounding it and encouraging accessing help:

> *'…Attending peer support groups enabled me to see that my depression was a common problem in our community and I've learnt different strategies to deal with negative thoughts that I was having.'*

We had regular attendees who found certain topics resonating deeply with their own experiences:

> *'I have learnt so much about different mental health topics, but I've found the session about dementia particularly helpful. I look after my grandma who has dementia, and I was able to learn how to support her better.'*

5.2.2 Synthesis

The Project made good progress in improving beneficiaries' understanding of mental health issues. Casework records and informal interviews with beneficiaries underpinned this data, revealing how beneficiaries began to draw connections between outward manifestations of distress (i.e., inability to sleep or uncontrollable crying) and mental health issues. The peer support group was a vital tool in propagating information about mental health within the Roma community, and meeting minutes indicated that beneficiaries became steadily more comfortable with disclosing mental health issues in the presence of other community members. As awareness of mental health issues increased, the Project team observed an increase in requests for referrals to secondary mental health services, reflecting growing awareness of service structures amongst beneficiaries.

For many beneficiaries, their engagement with Project activities represented the first time that they had actively addressed the topic of mental health. Often, they approached Project activities with a degree of scepticism, but as their understanding of mental health issues grew, they came to see the value of talking about mental health. Commenting on their experience of attending peer support group meetings, one beneficiary described how they were less likely to make assumptions about people who may be struggling with their mental health:

> *'I took part in peer support meetings so I have better view about mental health.'*

During the pandemic, we continued to offer peer support group meetings digitally, via Zoom. The sessions provided an opportunity for beneficiaries to meet others during lockdowns and share their anxieties and coping strategies. The sessions offered an opportunity for increasing awareness, including up-to-date information about COVID-19 and vaccination, learning new skills, and coping with difficult feelings that arose as a result of the pandemic. The feedback indicated that this in turn, enhanced beneficiaries' knowledge about health, self-empowerment and trust in services.

As these examples indicate, the Project's work in opening a dialogue about mental health had a substantial impact on understanding of mental health issues within the Roma community. Whether helping people to overcome the stigma associated with mental illness or helping people to identify sources of support, fostering understanding of mental health sparked a shift in the way that beneficiaries discussed their emotional issues and approached services for formal support.

Case study 1: Anxiety awareness session with a psychologist

Anxiety was one of the most common mental health issues for which beneficiaries sought out support from the Project, yet discussions during advocacy sessions revealed overall low levels of understanding of the practical impacts of anxiety and the types of support available through mental health services. To help answer these questions, the Project Coordinator invited the clinical lead from Waltham Forest Talking Therapies to deliver an awareness session on anxiety at one of the peer support group meetings. The clinical lead had a special interest in Roma communities, having run a Roma health discussion group at a GP practice where he had previously worked, and therefore understood how to provide culturally sensitive explanations of mental health issues.

Beneficiaries who attended the session were highly engaged in the discussion following the psychologist's presentation. One beneficiary described how she frequently experienced episodes in which her chest seemed to seize up and she felt as though she was unable to breathe, asking whether this could be a symptom of anxiety. Not only did the psychologist offer her immediate advice on steps she could take to manage these episodes, but he also offered her a direct referral to his service. As the Project team gathered feedback from beneficiaries following the session, they overwhelmingly expressed a much deeper knowledge of anxiety and most reported an increased desire to seek out support from mental health services.

5.3 Project impact in improving satisfaction with mental health services

5.3.1 Achieving Outcome 3: "Roma beneficiaries have increased level of satisfaction with mental health services."

The Project aimed to improve beneficiaries' satisfaction with mental health services by streamlining referral pathways, ensuring adequate provision of language support and providing professionals with information about the cultural beliefs that may impact on beneficiaries' mental health communication.

Beneficiaries' satisfaction with mental health services was measured through DTFs, satisfaction surveys and informal interviews. Annually, the Project made progress as follows:

- Year 1: 29% of beneficiaries monitored through DTFs reported increased satisfaction with mental health services

- Year 2: 70% of beneficiaries monitored through DTFs reported increased satisfaction with mental health services
- Year 3: 57% of beneficiaries monitored through DTFs reported increased satisfaction with mental health services
- Year 4: 50% of beneficiaries monitored through DTFs reported increased satisfaction with mental health services
- Year 5: 60% of beneficiaries monitored through DTFs reported increase in satisfaction and trust with mental health services

5.3.2 Synthesis

Observational data and beneficiaries' feedback indicated that the low levels of satisfaction with mental health services were directly associated with the unreliability of interpreting provision. Moreover, beneficiaries felt that appointment lengths and frequencies were insufficient to meet their needs. To address the issue with interpreting support, the Project began channelling beneficiaries through access and assessment teams, which seemed to ensure that sufficient interpreting support would be provided. The issue with appointment length and frequency could not be directly mitigated through Project activities, but the team did take steps to explain the extent of service provision available, thus helping beneficiaries to manage their expectations for mental health support.

To increase satisfaction with mental health services, the Project served as a mediator between Roma community members and service providers. Discussions with beneficiaries revealed that often it was not a lack of interest in receiving mental health support that deterred them from accessing services, but rather a fear of not being able to understand information from mental health professionals. By providing accessible mental health information, the Project afforded beneficiaries the foundational knowledge necessary to effectively communicate with mental health professionals, thus heightening their satisfaction with mental health services. One beneficiary whom the Project assisted to make a self-referral to talking therapies expressed the vital links between information, understanding and satisfaction:

> *'Everything was explained in a manner that allowed me to understand. I was referred to a psychologist and I am happy to go there.'*

We believe that peer support group meetings were instrumental in establishing trust and building bridges between Roma communities and mental health services. During the pandemic we continued to offer these meetings digitally, via Zoom. This offered a space to meet with other community members and professionals, which in turn, helped to strengthen trust between beneficiaries and clinicians. Some beneficiaries made decisions to access therapy after attending several group meetings:

'Peer Support Groups allowed me to meet mental health professionals and see that they just want to help. I then made a decision to access counselling.'

Peer Support Group on anxiety delivered by psychotherapist from CAMHS

Case study 1: Building trust between professionals and a patient in crisis

V. is a 16-year-old girl. Following her mother's diagnosis with breast cancer V. endured a prolonged struggle to cope with the possibility of life without her mother. Although the Project had previously referred V. to CAMHS, she insisted that she did not need mental health support. Without professional input, her mental health deteriorated substantially. She reached a breaking point in attempting to balance the demands of school and her caring responsibilities, which were becoming steadily more strenuous as her mother's health condition worsened.

Ultimately, she ran away from home, spent the night under a bus shelter and was found by the police the next morning. The police took her to an inpatient adolescent mental health facility, where she was sectioned.

She underwent an assessment at the mental health facility and was diagnosed with psychosis and depression. It was also during her assessment that V. disclosed that she is a lesbian, which, due to Roma cultural beliefs about homosexuality, had further heightened tensions with her family. V.'s parents feared that their reputation in the Roma community would be damaged. They have repeatedly expressed the hope that homosexuality is just a passing phase and that it can be cured. The Project Workers have made substantial efforts to explain the nature of homosexuality to V.'s family, and also to help her to gain a greater sense of self-acceptance despite family and community expectations. Although V.'s parents have been slow to accept their daughter's sexuality, they ultimately expressed that they just want her to get well again. The Project Workers additionally fostered improved communication with the numerous health and social care professionals involved in V.'s case. They also helped the family to build positive relationships with the professionals and to overcome their initial skepticism about professional involvement (particularly with regard to social services). Most importantly, the Project's input has been integral to V.'s gradual recovery, helping professionals to identify art therapy as an effective mode of engagement.

Case study 2

Z. (18 years old) lives with her parents and brother in a temporary accommodation. She was diagnosed with schizophrenia and started psychological treatment at the Child and Adolescent Mental Health Service (CAMHS). Since then, the Project has been working with Z. and the team involved in her care delivery. The Project workers attended regular clinical meetings, and sent each other updates on their work with Z., ensuring that she was receiving an adequate care.

At the beginning of the pandemic Z. turned 18, which prompted a transfer to the Adult Mental Health Service (AMHS). Such transition involved a dramatic culture change, particularly since the approach was less flexible, which in turn made Z. feel even more anxious. The Project workers were involved in this transition and ensured that Z. was given an additional support by referring her to a mentoring programme at a local charity organisation. She was offered weekly meetings with a volunteer that enabled her to address her social anxiety and go out for walks. Z.'s feedback was that this support was instrumental during the transition and pandemic and it improved her mental health and satisfaction with the mental health services.

5.4 Project impact in improving beneficiaries' sense of wellbeing

5.4.1 Achieving Outcome 4: "Roma beneficiaries with mental health issues report improved wellbeing."

The Project's holistic advocacy activities aimed to improve beneficiaries' overall sense of wellbeing, as well as to help them to become more confident in engaging with mental health services.

To assess this outcome area, DTFs asked beneficiaries to rate their overall sense of personal wellbeing, to assess the impact of mental health issues on their work and social activities, and to report on their sense of self-empowerment in accessing mental health services. Annually, the Project made progress as follows:

- Year 1: 43% of beneficiaries reported an increased sense of wellbeing; 43% additionally reported increased self-empowerment in using mental health services
- Year 2: 40% of beneficiaries reported an increased sense of wellbeing; 50% additionally reported increased self-empowerment in using mental health services
- Year 3: 64% of beneficiaries reported an increased sense of wellbeing; 57% additionally reported increased self-empowerment in using mental health services
- Year 4: 65% of beneficiaries reported an increased sense of wellbeing; 65% additionally reported increased self- empowerment in using mental health services
- Year 5: 75% of beneficiaries reported an increased sense of wellbeing; 70% additionally reported increased self-empowerment in using mental health services

5.4.2 Synthesis

To interpret these figures, it is vital to note that roughly 65% of Project's beneficiaries suffer from chronic, life-limiting and degenerative physical health conditions in addition to mental health issues. Measurements of wellbeing thus reflect the totality of an individual's health situation and not mental wellbeing alone. To provide additional insights into beneficiaries' broader life circumstances, DTFs gathered data on the impacts of mental health issues on beneficiaries' daily lives, revealing fluctuations in beneficiaries' assessments of the social impacts of mental ill health and perhaps suggesting a complex relationship between mental health issues and self-rated wellbeing.

For many beneficiaries, mental health issues were linked to and intensified by wider concerns about inadequate housing, debt and difficulties in accessing health-related benefits. While it could be difficult to establish the exact impact of these difficulties on beneficiaries' self-reported assessments of their mental health, it was likely that they were contributing factors in the high rates of anxiety and depression across the Project's beneficiary group. By referring beneficiaries to welfare and housing advice, the Project sought to improve beneficiaries' overall mental wellbeing. As beneficiaries began to feel more secure about their financial and accommodation situations, they reported substantial gains in their ability to cope with the stresses of daily life.

Our services were vital during the pandemic as we were able to outreach clients via phone and offer space for a chat and emotional support. Our beneficiaries reported that our services helped them to adjust to "the new normal", which in turn improved their overall wellbeing and ability to cope with problems and access relevant support digitally.

'I struggled with my mental health during pandemic, but the Project staff called me often to check-in that I was ok. I was able to talk to them about my problems and was told what might help. I always felt better afterwards.'

Case study: The intersection of physical and mental health

Case study 1

M. was nearing a breaking point as she battled cancer and grappled with housing insecurity.

When the Project team began our work with her, she explained how she would sometimes carefully clean her body to prepare for suicide, only to be held back by feeling of responsibility for her family.

The situation was urgent, the Project team needed to carefully consider all aspects of M.'s case before proceeding with a referral to mental health services. The team knew that she had previously engaged in talking therapy with a Polish-speaking psychologist and had found this to be extremely beneficial. After considering the range of mental health services available to her in Newham, as well as Polish-speaking psychologists outside the borough, the team decided to make a new referral to talking therapies. While some questions remained as to whether this would provide a sufficiently intense course of treatment given the deterioration in M.'s mental wellbeing, previous experience had indicated a straightforward trajectory from referral to assessment to treatment, and in this case efficiency was vital. Furthermore, given the complexity of her situation, the team hoped that talking therapy would offer a holistic view of coping strategies.

Upon beginning talking therapy, M. reported a rapid improvement in her sense of mental wellbeing. She had initially been sceptical of the efficacy of mental health services in helping her to manage the numerous complex stressors in her life, yet she found that engaging in talking therapy made her feel better equipped to cope with her physical health status and support her family.

This is not to say that there were no setbacks. After weeks of productive therapy sessions, M. received bad news related to her cancer diagnosis, which sent her once again into a spiral of confusion and fear.

Even at this time of extreme pressure, she still attempted to attend the appointment with her psychologist, yet in her disorientated state she took the wrong bus and missed the appointment. She contacted the team in tears, who then contacted her psychologist to explain her reason for not attending. Understanding the physical and emotional difficulties that she faces in leaving the house, the psychologist offered her a telephone appointment early in the following week.

With the support of the Project, M. began to see her mental wellbeing as a priority. Where she would never before been concerned about missing a therapy session, her response revealed the extent to which mental health care has come to represent a key component of managing her health situation.

Case study 2

A. is a 68-year-old woman living with her husband in Newham. She suffers from mild depression and anxiety and used to attend our peer support groups regularly prior to the pandemic. A's mental health problems were exacerbated during the first lockdown as she was constantly worried about her family getting COVID-19 and felt isolated from her community. She faced digital exclusion as she did not have access to the internet and suitable devices that would enable her to join our peer support groups or external psychological support. After discussing her case, a staff member was allocated the task of calling her every week for a brief chat, to discuss how she was coping and provide her with suggestions for improving her wellbeing. A. reported that such support was essential in reducing her feelings of loneliness and anxiety, and helping her adjust to the reality of the pandemic.

5.5 Project impact in improving professionals' knowledge of Roma health

5.5.1 Achieving Outcome 5: "Mental health service providers have increased awareness of Roma patients' needs."

The Project worked to improve professionals' knowledge of Roma health through direct support for professionals working with Roma beneficiaries, Roma cultural awareness training seminars for health professionals, and informational materials describing barriers to health care access faced by Roma communities with tips for successful engagement.

To assess the effectiveness of these activities, the Project gathered feedback forms from professionals attending training sessions and conducted informal follow-up interviews to gain insight into the usefulness of leaflets and training materials. Annually, the Project made progress as follows:

- Year 1: The Project supported a total of 164 professionals in their work with Roma patients, with 133 of the total engaging in training seminars and 31 receiving direct advice and support. 76% of training seminar participants reported that the sessions improved their knowledge of the Roma community, and 100% of health professionals who have received copies of the leaflet and direct support in working with Roma patients reported that our services are helpful and relevant to their needs.
- Year 2: The Project supported a total of 129 health professionals in their work with Roma patients, with 95 participating in the training seminars and an additional 34 receiving direct support. 80% of training seminar participants reported that the sessions improved their knowledge of the Roma community and 100% of health professionals who have received copies of the leaflet and direct support in working with Roma patients reported that our services were helpful and relevant to their needs.
- Year 3: The Project supported a total of 58 professionals in their work with Roma patients, with 27 of the total engaging in training seminars and 31 receiving direct advice and support. Feedback forms gathered during training sessions reveal that 100% report increased awareness of the Roma community. 100% of leaflet recipients reported that it increased their knowledge of successful methods of engagement with Roma patients.
- Year 4: The Project supported a total of 130 professionals in their work with Roma patients, with 75 attending our training and 55 receiving direct support. Feedback forms gathered during training sessions reveal that 100% report increased awareness of the Roma community. 100% of leaflet recipients reported that it increased their knowledge of successful methods of engagement with Roma patients.
- Year 5: The Project supported 112 professionals in their work with Roma patients. 68 of professionals were directly involved in supporting our beneficiaries and we engaged with an additional 59 through our online trainings. Feedback indicated that 100% of respondents reported increased awareness about Roma issues as a result of our trainings and through our information leaflets.

5.5.2 Synthesis

At the outset of the Project's engagement with health professionals, observational notes from training sessions and face-to-face meetings indicated low levels of awareness of Roma. Training participants in particular displayed an almost complete lack of awareness of Roma as a distinct ethnic group and of the presence of Roma populations in the areas covered by their services. However, once provided with information about Roma culture, discrimination against Roma and conditions of disadvantage, professionals reported intentions to actively counteract stereotyping and discrimination against Roma in their practice. The Project's network of contacts with mental health services in East and North East London expanded steadily over the Project's life, and Project team members observed that they were encountering fewer professionals with no prior knowledge of the Roma community.

A training session for the Newham Community Recovery Team

Professionals attending the training sessions described how they came into the training with very limited knowledge of the Roma community and culture, and their feedback highlighted substantial gains in knowledge:

> *'It was an eye-opener for us to know that there are different sections in the Roma community…They have different dialects as well. We, as health professionals, might be mixed up with it. People might not say they are Roma; they might say they're Polish, Romanian or Slovak. [The training] gave a clear idea about the community and how health services around them could support them.'*
>
> *'The online training was really informative and gave lots of detailed information about barriers to engaging with Roma people and practical advice of how best to seek to engage with Roma people, which is really helpful in supporting building links with this diverse community.'*

Another professional working in a GP practice described how she would make adjustments to her work after attending the training session:

> *'I think it was helpful to understand the patient... If you can understand them, you know how to approach them. .... If someone [i.e., Roma patient] does come along, I would be much more careful to ask them questions slowly, not to frighten them and to make sure they understand...'*

Despite the significant gains that the Project made in improving professionals' knowledge of Roma culture and health concerns, it is important to note that a small number of professionals engaged through training expressed open anti-Roma prejudice. The case study (2) below provides an example of this issue.

Case study 1: Identifying new areas for advocacy

One of the Project's training sessions for health professionals was attended by two specialist practitioners working with rough sleeping Roma, which offered insight into a largely unexplored area of mental health advocacy support. Street homeless Roma people represent an under-served population within mental health services, as their vulnerable and precarious living situations often put them outside the reach of formal support. Professionals may furthermore be unaware of their cultural perceptions related to mental health and thus be unable to provide culturally sensitive support. The training session attendees described the difficulties of communicating with Roma service users across language and cultural barriers. The discussion was illuminating for the Project team, as we had not previously engaged with street homeless Roma. While considering effective methods for fostering engagement between health services and rough sleeping Roma, we considered the possibility of collaborating with these services to produce culturally specific audio and visual materials in community languages. This represented an important development in our beneficiary engagement strategies, leading us to review our outreach methods in working with some of the most disadvantaged members of the Roma community.

Specialist homelessness nurses who attended the training furthermore emphasised how it provided vital information for carrying out future work with Roma patients. One commented: *'I'm still talking about [the training] with my team, my husband, everyone I meet because I found [the training] so valuable!'*

Case study 2: Challenges encountered in GP training sessions

A Roma Support Group representative attended a series of meetings between GPs, practice managers and a CCG facilitator, for which the RSG prepared a brief presentation on Roma culture and health-related beliefs. When the RSG presenter discussed Roma origins, one of the participants, a GP, shared his prior knowledge of the Roma community, explaining details of their migration history. While his initial contribution stimulated productive discussion of Roma culture, it soon emerged that the GP's research into the Roma had arisen from a news article about a Roma woman who had allegedly engaged in benefit fraud. He then went on to make generalisations about Roma community members' purported unwillingness to work and their reliance on fraudulent benefits claims. The presenter and the CCG representative emphasised that this misinformation was counterproductive to the goals of the meeting and attempted to steer the conversation back toward the topic of health in Roma communities. The GP, however, persisted in making inaccurate claims about criminal behaviour.

The GP did not appear to have a malicious intent in making these misleading statements about

Roma communities, but it nonetheless reveals the pervasiveness of harsh media portrayals of this ethnic group, as well as the manner in which many members of the general population consider these frequently sensational accounts of Roma life to be factually accurate. Prejudices and discrimination against the Roma have been characterised as the “last acceptable racism”, and otherwise tolerant individuals may voice derogatory views of these communities on the basis of an untrue, yet widespread, conception of the moral deficiency of Roma people.

Taken as a whole, the Project’s implementation of the Roma Culture Awareness training programme proved to be a vital means for helping professionals to overcome prejudices towards Roma, as was evidenced by comments from health professionals attending training sessions delivered in GP practices:

> *‘This has changed my perception and boosted my confidence to work effectively with this community.’*

Another professional commented:

> *‘I feel more knowledgeable and less likely to stereotype.’*

6. Reflections on learning questions

6.1 What barriers did beneficiaries encounter in accessing mental health services and what steps did the Project take to manage these?

Tracking beneficiaries’ ‘journey’ through mental health services has revealed a number of structural inefficiencies in their operation, which impact on both service accessibility and beneficiaries’ impressions of service effectiveness. Despite recent steps to enhance the accessibility of mental health services (e.g., through the introduction of the Improving Access to Psychological Therapies (IAPT) programme), service-level efforts to streamline referral procedures can reduce attention to the needs of patients from marginalised communities.

The referral mechanism for many IAPT services consists of an initial online referral form, followed by a telephone assessment. While this may superficially appear to give patients more autonomy in self-referring to mental health services, it in fact created a system that was impenetrable for many beneficiaries. There are low levels of IT literacy within the Roma community, often making independent navigation to the online referral form unachievable. This, however, can be remedied through the assistance of a mental health advocate. The greater challenge arises at the stage of the telephone assessment, when lack of interpreting support during the phone call creates an insurmountable barrier to entry into the service. The Project team made administrators within primary psychological services aware of this issue, requesting that language support be provided at the point of assessment, yet services remained rigid in their operating procedures. When attempting to secure a referral to a South London psychological service, for example, the Project made contact with the service immediately upon completing the online referral form to make them aware of this patient's need for language support. The service administrator replied that they employ two psychologists speaking the required community language, and that one of them could conduct the assessment, yet this could only be arranged after the patient had sent an email from a personal email address (which she did not have). Ultimately the service administrator agreed that the interpreter request from a Project worker's email address, yet this was only after the service management agreed to make an exception. This created a delay in the provision of support, placing a beneficiary who was already struggling with her mental health in a position of greater uncertainty and insecurity.

Challenges in navigating mental health services also extended beyond the point of initial referral. Many beneficiaries who had completed the standard course of cognitive behavioural therapy (the most common form of psychological support available through NHS primary mental health services) found that there was no clear mechanism for continuing treatment or easily receiving referrals to secondary mental health services if issues persisted. There was a common impression amongst beneficiaries that, because primary psychological services did not bring their mental health issues to a point of resolution, the natural next step was to access secondary mental health services. Assessment teams, however, tended to route beneficiaries back to primary mental health services, even when patients specifically requested more enduring and intensive support. This could in turn decrease beneficiaries' confidence in services, leading to discontinuation of engagement and reliance on medications to manage their mental health needs.

To address this issue, the Project team discontinued its initial practice of supporting beneficiaries in referring themselves to talking therapies (unless beneficiaries specifically requested this form of support). Instead, the Project made referral requests to local access and assessment teams, as the referral request forms for these services provided space to specify which level of mental health care provision a beneficiary wished to access, and furthermore enabled the team to detail each individual's language support needs. Although this method did not uniformly result in referrals to the preferred service, it did provide a mechanism for making services aware of the challenges that beneficiaries faced.

These structural flaws of the NHS, long waiting lists and high entry criteria for primary mental health services resulted in 27% (Year 4) of our referrals not being accepted. In addition, some clients reported feeling misunderstood by health professionals and were unable to access language support. This inevitably influenced their trust in services and willingness to access them.

On one occasion, our referral was not accepted because the assessor did not check the supporting letter from the community psychiatrist. This beneficiary had been sent from one service to another for a couple of months and because her diagnosis was unclear, she did not meet the criteria for therapy in either of the services. It took eight months and the involvement of three services before she accessed treatment. She commented:

> *'There was a lot of miscommunications between different teams and I kept being sent from one place to the other. It affected my trust in the services.'*

With the pandemic, all mental health services were being offered digitally and many referrals were being put on hold for months. As such, the pandemic inevitably affected access to services and many people failed to get the support. Many of our beneficiaries (particularly the elderly) who either did not have access to the internet and devices, or were unable to use them, faced digital exclusion. Some of them also faced more difficulties with booking interpreters for their online appointments. Additionally, with the statutory mental health services already stretched, there was an increase in demand and severity of new referrals during lockdowns, which affected waiting times. To counter these effects, we assisted our beneficiaries in developing new skills related to accessing digital appointments, which increased their independence in maintaining engagement with health services. Furthermore, peer support groups offered via Zoom were instrumental in maintaining the trust between beneficiaries and professionals.

Beneficiaries felt empowered to make positive choices about their mental health through learning new skills:

> *'The Project staff taught me how to use Zoom and other apps and helped me with a referral to therapy. I needed to wait a while but once I got a digital appointment, I was able to access it.'*

Health professionals also reported being able to engage with their patients after they were taught how to use Zoom:

> *'Because the client had limited English, we struggled to explain to her how to access her appointment. Roma Support Group were essential in helping her develop the necessary skills.'*

6.2 To what extent did the peer support model employed by the Project enhance beneficiaries' self-empowerment in accessing mental health services and learning about mental health issues?

Peer support group meetings delivered in the early months of the Project brought together small groups of beneficiaries to discuss their mental health concerns, with discussions led by the Project team. These early meetings centred on topics such as anxiety and depression, and introduced coping mechanisms such as mindfulness. While providing beneficiaries with an introduction into key topics in mental health, the depth of discussion could be limited by beneficiaries' lack of vocabulary for expressing their emotions and their lack of prior experience in communicating about mental health.

Following our consultations with participants, the peer support group model was developed in collaboration with beneficiaries who suggested a list of topics of interest and expressed willingness to meet health professionals from various external agencies. The Project Coordinator was able to invite professionals to co-deliver awareness sessions on depression, anxiety, addictions, dementia and fibromyalgia. They also talked about their work, the support available through their services and mechanisms for obtaining referrals.

Roma beneficiaries were then invited to ask questions, and in some cases, professionals prepared interactive activities to help increase beneficiaries' overall health awareness (e.g., delivery of blood pressure and blood sugar checks, which resulted in immediate GP referrals if these levels were outside the healthy range). Session topics also included heart health, diabetes and physiotherapy, and while these were not specifically focused on mental health, they helped to draw a wider range of beneficiaries into the peer support programme, reaching beneficiaries who may have avoided Project activities out of fear of engaging with the topic of mental health.

As beneficiaries engaged in discussion, many drew connections between symptoms described by the health professionals and emotional changes that they had observed either in themselves or their family members. They could then ask professionals directly whether they thought that these changes might indicate a mental health issue, and although it was not possible to provide a diagnosis during the peer support session, beneficiaries were provided with advice on where they could go to seek out support.

For many beneficiaries who attended peer support group meetings, the opportunity to engage with health professionals outside of a formal consultation setting boosted their confidence in communicating about their mental health concerns and seeking out support. Some beneficiaries requested referrals directly from the professionals delivering the sessions; others approached Project staff after the sessions with requests for referrals. In light of the fear and shame reported to accompany Roma community members' disclosure of mental health issues, peer support group participants' decisions to actively seek out mental health support suggests that the meetings sparked a shift in beneficiaries' perceptions of mental health. Not only did the peer support group model open discussions about mental health, but it also provided reliable information about the nature of mental health issues, combatting stigmatisation through heightened understanding.

As one of our beneficiaries shared with us, peer support group’s meetings were instrumental in challenging her pre-conceptions about mental health and accessing support:

> *‘I was always afraid that if I talk about my problems, my children might be taken away. The sessions helped me to understand that this would not happen just because of my depression. This empowered me to access psychological support.’*

During the pandemic we continued to offer peer support group meetings digitally, via Zoom. The sessions provided an opportunity for beneficiaries to meet others during lockdowns and share their anxieties and coping strategies. The sessions offered an opportunity for increasing awareness and knowledge on up-to-date information about COVID-19 and vaccination, learning new skills, and coping with complex feelings that arose as a result of the pandemic.

Beneficiaries reported experiencing enhanced sense of self-empowerment, trust in services and increased confidence in making positive choices related to their health as a result of the sessions. In addition, we assisted our beneficiaries in developing new skills related to accessing digital appointments, which in turn increased their independence in maintaining engagement with health services.

6.3 What were the dynamics underlying mental health professionals’ uptake and reception of the Project’s offer of Roma Culture Awareness training?

In Years 1 and 2 of the Project, the team was afforded an opportunity to participate in the delivery of a Roma Culture Awareness training programme for health professionals in the London Borough of Newham. This piece of work was based on a 2014 survey of Roma Support Group’s beneficiaries’ experiences of using GP services, which resulted in the identification of 11 GP practices with the largest number of registered Roma patients. The goal of the training programme was to deliver in-house training seminars to these GP practices.

The Project team also decided to extend the training offer to secondary health services, meeting with managers within East London Foundation Trust and Newham Community Health Services to discuss the possibility of advertising the training through their contact networks. While all secondary mental health services in Newham took up the training, engaging GP practices remained a challenge. It was ultimately only with repeated prompting from the Newham CCG that GP practices agreed to participate in the training programme.

The difficulties of engaging GP practices in the Roma Culture Awareness training, raised concerns about the extent to which primary care services are committed to addressing the specific needs of disadvantaged minority patient groups. It is possible that GP practices were reluctant to take up the training simply because there was limited time to incorporate additional activities into already full working days, yet this would suggest that levels of strain on primary care are so great that they prevent practice staff from developing relevant knowledge and skills. Often it was only by offering very abbreviated, 30-minute training sessions that the Project was able to persuade GP practices to participate in the training programme. While these short sessions served the minimum purpose of informing GP practices of some of the challenges that Roma patients face in accessing services, their effectiveness in prompting practice staff to meaningfully reflect on best practice in engaging with Roma patients was limited.

In light of the limitations of short, in-house training sessions, Years 3-5 saw a shift towards full-day, intensive training sessions. Although short sessions were effective in reaching a large number of health professionals, delivering a smaller number of longer sessions allowed the Project to more effectively build relationships with the professionals attending the training and explore complex cases involving their Roma patients. In some cases, the training programme also provided opportunities to make plans for future collaboration with services. By engaging in-depth with professionals who had varied experiences of working with Roma patients, the Project team was not only able to offer advice on effective engagement and communication, but also gained insight into issues that had not previously arisen through direct advocacy work. The training participants asked difficult and challenging questions, and as training facilitators and participants collaboratively sought to formulate answers, the Project team developed new ideas for engaging with beneficiaries in the future.

When considering the different models of professional training implemented over the Project's life, the longer in-depth sessions stand out as the most effective method for sparking discussions of good practice in providing health care for Roma patients, and for developing future working relationships between the Project and health professionals. Some health professionals who took part in our full-day training had worked with Roma patients in the past, but most professionals attending our training had little to no prior knowledge and understanding about Roma culture and attitudes to health. Occasionally, some participants showed signs of prejudice and misconceptions about Roma as in our case study on page 56.

Health professionals were able to engage in the sessions and enjoyed the interactive quizzes that enhanced their learning:

> *'Materials were clear, interactive and varied which kept all attendees engaged. The quiz was a great way of providing lots on facts and information in a really engaging way, that has made the information provided more memorable.'*

We were provided with a feedback that indicated that our sessions were instrumental in raising awareness about Roma culture, models of engagement and barriers that Roma face in accessing health services, which in turn challenged professionals' pre-conceived notions and enhanced their empathy and understanding towards Roma:

> *'Both speakers were very knowledgeable. I've gained a better understanding of Roma culture and different issues that they face and that might have an impact on their mental health. It will certainly inform the approach I will take in working with them.'*

7. Discussion

7.1 Strengths of the Project

7.1.1 Sparking discussion of mental health

One of the Project's key achievements was the extent to which it sparked a shift in perceptions of mental health within the Roma community. In the first months of the Project, Roma community members predominantly viewed disclosure of mental health issues as a source of shame, which one beneficiary succinctly captured with the comment:

> *'Before I didn't want to use mental health services. With support from RSG team I've started to use them.'*

The team initially described the Project simply as a 'health' project and offered a broad base of advocacy support in areas such as making GP appointments and requesting interpreters. Despite the potential stigma associated with the topic of mental health, there were nonetheless a number of beneficiaries who came forward and requested support in accessing mental health services. Word gradually spread within the community regarding the Project team's effectiveness in achieving results, and increasing numbers of beneficiaries actively began to seek out the Project's services.

Increasing numbers of beneficiaries furthermore developed vocabulary related to mental health, and by the end of the Project, beneficiaries moved beyond simple descriptions of feeling 'happy' or 'sad' to offer more nuanced descriptions of feeling depressed, stressed and overwhelmed. This increase in knowledge demonstrates the effectiveness of direct peer advocacy sessions in helping community members to develop their knowledge of mental health, and it is likely to have long-term impact in improving beneficiaries' future interactions with mental health service providers.

The Roma community commonly associates acknowledgement of emotional difficulties with shame and weakness. While this does not mean that discussion of mental health cannot occur, the Project was effective in framing topics in a way that was acceptable in the context of Roma cultural beliefs related to health. To stimulate open discussion about mental health and wellbeing, the Project team and beneficiaries identified topics that resonated with people emotionally and reflected experiences shared by many community members. For example, the Project hosted peer support group meetings that broadly addressed the emotional impacts of immigration insecurity, and beneficiaries' discussions captured the feelings of depression and anxiety stemming from the fear that they may one day be forced to leave the UK. By linking mental health to the practical realities of beneficiaries' lives, the Project was able to introduce unintimidating and open discussions about mental wellbeing. During the pandemic it was vital that the Project continued to offer a safe space for people to feel connected to their community through discussing shared experiences of surviving the COVID-19 crisis. Our beneficiaries reported that digital peer support groups enabled them to feel less lonely and anxious and to learn how to cope with feelings of fear, loss, insecurity and uncertainty.

7.1.2 Fostering direct contact between Roma patients and health professionals

Many beneficiaries approached mental health services with a degree of scepticism. This seemed to originate from a combination of uncertainty about the effectiveness of psychological therapies and fear that other members of the community would find out about an individual's mental health concerns. By inviting mental health professionals to deliver short presentations at peer support group meetings, beneficiaries were able to overcome some of their internal barriers to discussing mental health issues and accessing services.

Delivering the peer support component of the Project represented a consistent learning experience for all members of the Project team, as the model for peer support delivery was continually updated and revised based on feedback from beneficiaries. In their earliest design, peer support group meetings took the form of an open forum where beneficiaries could discuss sources of distress in their lives, with discussion topics focusing on depression, anxiety and mindfulness. The Project team was able to provide basic advice on services for addressing their mental health concerns, yet some beneficiaries expressed an interest in more immediate answers to their questions about mental health. To address this, the team adjusted its methods of peer support delivery to incorporate direct engagement with health professionals. This involved short awareness sessions delivered by professionals, during which beneficiaries could ask questions and share their experiences.

In many cases the Project engaged with professionals who were themselves from minority ethnic backgrounds, and they were able to share examples of coping with mental health stigma from their own communities. This perhaps helped beneficiaries to overcome their hesitation to discuss mental health issues, and also provided them with practical examples of coping mechanisms. Beneficiaries attending peer support group meetings were active in seeking out information, and they found the peer support programme most effective when it offered them concrete ways for improving their quality of life. To ensure beneficiaries continued and active engagement in the peer support programme, the team learned that it is vital to provide them with tangible and useful information.

7.1.3 A whole-family approach to complex cases

As the Project's casework grew considerably in complexity, the Project team engaged in regular and intensive support meetings, not only with people experiencing mental health issues, but also with their family members. Taking this whole-family approach was effective in ensuring that people experiencing mental distress received as much support as possible, and has also helped family members to overcome some of the stigma associated with mental ill health. Given the persistent fear of mental health issues in the Roma community, it was vital to offer clear explanations of mental health diagnoses and prognoses both to patients and their families. Once beneficiaries and their families had a better understanding of the nature of mental health issues and what to expect from the future, they were more prepared to work towards recovery. In other cases, when one member of a family was experiencing severe mental issues, other family members began to exhibit associated symptoms of anxiety and depression. The Project team's involvement prevented carers of people with severe mental health issues from becoming overwhelmed with their caring responsibilities and falling into mental ill health themselves. The Project assisted family members in securing referrals to relevant therapies, communicating with service representatives and keeping track of their appointments, thus allowing them to focus on their wellbeing.

Case study: Individualised support across generations

A., a Slovak Roma woman, was initially reluctant to engage with the Project as she sought out support with her daughter's claim for Personal Independence Payment (PIP). As the appointment progressed, A. expressed her concerns about her daughter's behaviour, which was becoming increasingly withdrawn. The Project team explained the options for mental health support that were available to her daughter, and A. agreed to a referral to the local Child and Adolescent Mental Health Service (CAMHS). Despite initial scepticism about the effectiveness of mental health services, when she returned to the Project team to report on the successful outcome of her daughter's PIP claim, she also described the positive changes in her daughter's behaviour that stemming from her involvement with CAMHS.

From this point on, A. made regular appointments with the Project team, seeking out assistance for her son, who struggled with learning difficulties. The Project team referred her son to an educational psychologist, which allowed A. to better understand his abilities and to make plans for his future education.

A. frequently expressed how she felt overwhelmed in managing her children's complex support needs and felt sometimes that she was sacrificing her personal wellbeing to look after her children. Although the Project team explained that mental health services could help her in coping with the numerous stressors in her daily life, she declined all offers of assistance in obtaining a referral, maintaining that she did not have time to attend appointments with a psychologist. The Project may not have led her to access formal mental health support, yet her regular meetings with members of the team offered her an outlet to express her frustrations, and also provided her with necessary respite from her caring responsibilities.

In this case the Project supported multiple family members, with varying support needs, to develop individualised approaches to managing their mental health situations. Sometimes this was through direct referrals for professional support, and at other times it was simply through listening to their needs.

7.1.4 Supporting beneficiaries in the transition from face-to-face to digital appointments

The transition from face-to-face to digital appointments involved many complexities, however it has proven to work well for many beneficiaries. We were also able to outreach more people from outside of London, who were able to attend our digital peer support groups. This in turn enabled us to deepen engagement, and for beneficiaries, to enhance a sense of community through their shared experiences. Digital conversations and meeting new people who struggled with similar problems related to the pandemic, allowed them to feel less lonely, and we were able to offer support to new beneficiaries, who often had not previously accessed any mental health services. Furthermore, people were taking more responsibility for their mental health recovery through learning digital skills and ensuring they were proficient enough to access the sessions.

7.2 Limitations of the Project

7.2.1 Sustaining contact with beneficiaries accessed through health-related welfare advice

Taking a holistic approach to mental health advocacy, whereby supporting beneficiaries in accessing mental health services alongside raising awareness about other determinants of mental health, was important in building trust with beneficiaries and equipping them with tools to sustain their overall wellbeing. Appointments and referrals associated with mental health-related welfare claims demonstrated our sensitivity to complex issues faced by Roma, and were sometimes used as an entry-point to the Project for those who were hesitant to acknowledge their mental health needs.

Although demand for assistance with health-related welfare advice was high, the time devoted to completing health-related benefits applications was reducing the time available for conducting dedicated mental health advocacy work and undertaking outreach work with the most vulnerable members of the Roma community. To address this issue, the team were instrumental in strengthening Roma Support Group’s system for internal referrals, so that anyone approaching the Project with requests for non-mental health-related assistance was automatically referred to our advice and advocacy projects (or an external agency). This helped to ensure that beneficiaries continued to receive holistic support and enabled the Project team to focus on mental health advocacy, outreach and follow-up work.

Furthermore, to encourage further involvement in the Project, we developed a system for regular follow-ups with beneficiaries, who had disengaged after having their benefit claim submitted.

7.2.2 Finding solutions for digitally excluded beneficiaries

Some beneficiaries, who used to attend the Project activities regularly prior to the pandemic, were often unable to access them online. Although we provided digital skills trainings in different languages to ensure that our beneficiaries could access our peer support groups, some did not have access to the internet, or devices that would allow them to use such platforms. We tried to find solutions and worked alongside other organisations to improve access to digital services in the hope that there would be more opportunities for people to access free/cheaper internet/devices, however that was often not possible.

7.2.3 Ensuring an effective referral process

Due to limited criteria for access in primary mental health services, approximately 30% of our referrals each year were rejected resulting in automatic closure of cases, while a renewed referral could not be submitted for 90 days. The reasons for not accepting referrals were often erroneous and inconsistent (see page 59 for example). These structural flaws in the NHS have direct impact on our beneficiaries’ health and their trust in services. We continued to address these issues with service managers and commissioners and used peer support groups to restore beneficiaries’ trust.

7.3 Recommendations for further work in the area of Roma mental health

The combination of our mental health and health/wellbeing focused work, as well as our consultations with Roma community members and external agencies, has given us considerable insight into and awareness of:

- The mental health needs of the Roma community in London
- The barriers Roma face in accessing mental health services

- The most effective ways of enhancing engagement with Roma people who are managing mental health issues

7.3.1 Developing mental health advocacy work in Roma communities

Our Project's findings and the results of our consultations have confirmed the need to develop mental health advocacy in Roma communities, focusing on:

- Improving communication strategies with Roma who have mental health issues to overcome the stigma attached to mental health in the Roma community
- Trust-based, one-to-one mental health advocacy to represent, empower and guide beneficiaries through the system in order to overcome their fear and mistrust of the medical establishment
- Holistic and individualised approach to Roma beneficiaries' needs to improve the quality of their lives
- Recognising and working with educational disadvantage and language barriers of Roma beneficiaries by using bi-lingual advocates
- Supporting Roma beneficiaries in the process of self-development and social engagement through peer advocacy programme
- Engaging with mental health professionals to increase their knowledge of Roma culture and enhance their understanding of Roma patients' needs and more effective interventions

7.3.2 Expanding the state of research on Roma health

The Project – as well as our previous work on Roma mental health – suggests that mental health issues put substantial pressure on members of the community. At present, however, there is little robust research on the prevalence of mental health issues in Roma communities, the barriers community members face in accessing mental health services and the nature of interaction between Roma patients and mental health professionals. There is an urgent need for the collection of national health data on Roma migrant communities in the UK, as available evidence suggests that this group faces disproportionate health inequalities yet remains largely invisible within health service provision decisions.

8. Appendices

8.1 Monitoring forms

Roma Mental Health Advocacy Project

Entry Form

Date completed: ____________________________________

General Information

Name		
Place of residence	Borough	Postcode
Primary language spoken		

Health Information

Do you have any physical and/or mental health problems or disabilities?	Yes Please specify:		Don't know		
How much do these problems affect your day-to-day life?	Very much	Quite a bit	It varies	A little	Not at all
Do you have a GP?	Yes		No	Don't know	
What is your GP's name and address?					

Are you accessing any specialist services?	Yes	No
If yes, what services?		

If you have any mental health problems, what help were you offered? (Tick all that apply)

Medication	
Counselling	
Self-help group	
Special education support	
Hospitalisation/mental health clinic	
Psychiatric treatment	
Social care services support	
Neurological treatment	
Speech therapy	
I was not offered any help	

Comments:

Initial Assessment Form

Roma Mental Health Advocacy Project

Client's name:

Date:

Referred by	Name	Organisation/Relationship	
Mental Health Problems			
Other Health Problems			
Concerns			
Carer (If Applicable)	Name	Relationship	Contact Number

Comments:

ROMA SUPPORT GROUP

Mental Health Advocacy Project Referral Form

Name:	Date of referral:
Address: GP:	Telephone number: Email address:
Name of the referrer: Referrer position and service:	Consent: Y/N

Reason for referral. Please include presenting problems, their history and current context:

Risk:
Reasonable adjustment: - Does the person have a condition that requires an adjustment to ensure access (e.g. LD, ASD, ADHD, physical disability, sensory impairments)?
Physical health: ➢ Does the person experience physical health problems? ➢ If yes, what are those and what services are they open to?
Social needs assessment: ➢ Housing situation, financial security, immigration status?

For referral queries please contact:
The Project Coordinator (Daria Ferranti)
daria@romasupportgroup.org.uk
07310172379

ROMA SUPPORT GROUP

Mental Health Advocacy Project

Support Plan

1. Date of the assessment:

2. Advocate:

3. Name:

4. Address:

5. Contact:

6. Next of kin:

7. GP address:

Presenting problem:

Plan of action:

Action Plan

Roma Mental Health Advocacy Project

Client's name:

Date:

Actions (agreed upon by Mental Health Advocate and service user)	Who will take the action

Service User

Name: Date:

Signature:

Mental Health Advocate

Name: Date:

Signature:

Roma Mental Health Advocacy Project

Distance Travelled Form

Date completed: ______________________________

1. Overall, how would you rate your health and wellbeing? (1 = Very bad, 10 = Very good)

1	2	3	4	5	6	7	8	9	10

2. How much do you feel that mental health problems affect your work, social activities or any other aspect of day-to-day life? (1 = All the time, 10 = Never)

1	2	3	4	5	6	7	8	9	10

3. How much do you know about mental health issues? (1 = Nothing, 10 = A lot)

1	2	3	4	5	6	7	8	9	10

4. How much do you know about which mental health services are available in your area? (1 = Nothing, 10 = A lot)

1	2	3	4	5	6	7	8	9	10

5. How easy or hard do you feel it is to access mental health services? (1 = Very hard, 10 = Very easy)

1	2	3	4	5	6	7	8	9	10

6. How confident do you feel in explaining your needs to mental health professionals? (1 = Not confident at all, 10 = Very confident)

1	2	3	4	5	6	7	8	9	10

7. How satisfied do you feel with the mental health services you have used? (1 = Not satisfied at all, 10 = Very satisfied)

1	2	3	4	5	6	7	8	9	10	N/A

8. How well do you feel that your doctors understand the Roma community and culture? (1 = Not at all, 10 = Very well)

1	2	3	4	5	6	7	8	9	10

9. Is there anything else you would like to tell us about your personal problems or any help you might need?

Roma Mental Health Advocacy Project

Distance Travelled Form

Data wypelnienia: ______________________________

1.Ogolnie, jakbys ocenil/a swoje zdrowie i samopoczucie? (1 = bardzo zle, 10 =bardzo dobrze)

1	2	3	4	5	6	7	8	9	10

2. Jak bardzo problemy natury psychicznej wplywaja na twoja prace, kontakty z ludzmi i na inne aspekty dnia codziennego (1 = caly czas , 10 = nigdy)

1	2	3	4	5	6	7	8	9	10

3. Jak duzo wiesz na temat depresji i podobnych problemow ? (1 = Nic, 10 = bardzo duzo)

1	2	3	4	5	6	7	8	9	10

4. Czy wiesz jaka pomoc oferuje sluzba zdrowia w twojej okolicy ludziom zborykajacym sie z depresja i innymi chorobami o podlozu psychicznym ? (1 = nic nie wiem, 10 = wiem duzo)

1	2	3	4	5	6	7	8	9	10

5. Jak latwo badz jak trudno jest uzyskac pomoc w leczeniu depresji i innych problemow podobnej natury ? (1 = bardzo ciezko, 10 = bardzo latwo)

1	2	3	4	5	6	7	8	9	10

6. Jak pewny/pewna siebie sie czujesz w uzywaniu pomocy z zakresu zdrowia psychicznego ? (1 = w ogole nie czuje sie pewnie , 10 = bardzo pewnie)

1	2	3	4	5	6	7	8	9	10

7. Czy byles zadowolony/a z pomocy jaka uzyskales korzystajac z roznych form pomocy osobom cierpiacym na depresje i podobne choroby (1 = w ogole niezadowolony/a, 10 = bardzo zadowolony/a)

1	2	3	4	5	6	7	8	9	10

8. Jak wedlog Ciebie doktorzy rozumieja spolecznosc romska i ich kulture? (1 = nic nie wiedza, 10 = bardzo duzo wiedza)

1	2	3	4	5	6	7	8	9	10

9. Czy cos jeszcze chcialbys/chcialabys dodac odnosnie swoich swoich problemow badz pomocy ktorej bys oczekiwal/oczekiwala?

Satisfaction Survey

Roma Mental Health Advocacy Project

Imie: ____

Data wypelnienia: ____________________________

1. Czy przed tym appoitmentem/ wziyta wiedziales/as gdzie szukac pomocy w przypadku roznych dolegliwosci?

Tak	Nie	Nie jestem pewny/a

2. Czy byles/as wstanie umowic sobie wizyte do specjalisty, ktory wydawal ci sie najlepszym rozwiazaniem w przypadku twojej choroby?

Tak	Nie	Nie jestem pewny/a

3. Jak dobrze mogles sie porozumiewac ze swoim lekarzem specjalista?

Niedobrze	Nie za dobrze	Srednio	Calkiem dobrze	Bardzo dobrze
1	2	3	4	5

4. Jesli sluzba zdrowia zapewnila ci tlumacza, czy wszystko co tlumacz ci mowil bylo zrozumiale dla ciebie? jak oceniasz wasza wspolprace ?

Niedobrze	Nie za dobrze	Srednio	Calkiem dobrze	Bardzo dobrze	Nie dotyczy/ mialem/mialam wlasnego tlumacza
1	2	3	4	5	

5. Czy uwazasz, ze leczenie, ktore ci zaproponowano odpowiadalo twoim potrzebom?

Tak	Nie	Nie jestem pewny/a

6.Czy byles/las zadowolony z przebiegu wizyty?

Nie	Nie za bardzo	Srednio	Raczej tak	Bardzo zadowolony/a
1	2	3	4	5

Roma Mental Health Advocacy Project

Feedback Form

Name: ____

Date: ____

1. Do you find the advice and support provided in the mental health project useful?

Yes	So-so	No

2. Were you happy about your contact with our staff members and volunteers? Do you feel they treated you well?

Yes	So-so	No

3. Which project activities have you used?

- ✷ Face-to-face advocacy sessions
- ✷ Peer support group meetings

4. Has the project helped you learn more about mental health?

Yes	So-So	No

5. What is the most useful thing about the Mental Health Advocacy Project?

____

____

____

____

____

6. What have you done to manage your mental health?

- ✷ Talking therapy
- ✷ Mental health assessment
- ✷ Specialist mental health services
- ✷ Medication
- ✷ None of the above

7. Has the project made it easier to use mental health services?

Yes So-so No N/A

8. Do you feel that mental health services have helped you with your problems?

Yes So-so No N/A

9. Would you like to change something about the Mental Health Advocacy Project? If so, what would that be?

Yes No

____

____

____

____

____

8.2 Leaflets for Roma beneficiaries

Note: all leaflets for beneficiaries were available in both English and Polish.

PROJEKT ZDROWOTNY

Czy czujesz sie smutny/a zdolowany/a?

Czy trudno ci sie porozumiec ze swoim lekarzem?

Nasz zespol moze ci pomoc!!!

Zadzwon 07775819910

Albo wpadnij do biura w piatek I porozmawiaj z Szymonem, Edyta lub Sarah.

Cierpisz na jedno z ponizszych?

Niskie samopoczucie
Ciągłe uczucie niepokoju
Brak odczuwania przyjemnosci
Bezsennosc lub nadmierna sennosc

Pracownicy naszego Projektu Zdrowia Psychicznego mogą ci pomóć !

Zadzwon w srode pomiedzy godzina 11 a 13 pod numer 07445548279 i popros o wizytę z Szymonem, Darią lub Edytą.

ROMA
SUPPORT GROUP

MENTAL HEALTH PROJECT

Do you often feel low and depressed?

Do you struggle to communicate with your GP?

We can help you!!!

Please call us on Wednesday between 11am and 1pm on 07445548279 and ask for an appointment with Szymon, Daria or Edyta.

WHAT IS MENTAL HEALTH?

Mental health is how we feel about ourselves and other people.

Everyone has mental health, and sometimes people will have problems with their mental health.

WHAT ARE SOME COMMON MENTAL HEALTH ISSUES?

Depression

You might be depressed if you feel sad or lose interest in things you used to enjoy.

Anxiety

You might have anxiety if you spend a lot of the time feeling nervous or worried.

EVERYONE FEELS THIS WAY SOMETIMES.

HOW DO I KNOW IF I NEED HELP?

You might want to get help with your mental health if emotional problems keep you from doing the things you want to do.

WHAT CAN I DO IF I AM HAVING MENTAL HEALTH PROBLEMS?

- Attend therapy sessions and talk about your problems with a professional. The RSG Mental Health Team can make a referral.
- Talk to your GP. They can refer you to mental health services or prescribe medication.

ROMA SUPPORT GROUP

The Roma Mental Health Advocacy project can help.

Call 07775 819 910 for an appointment.

8.3 Leaflets for health professionals

ROMA
SUPPORT GROUP

Working with Roma in a Health Context

This is an informational leaflet for health professionals and NHS personnel. All Roma customs and taboos were researched in collaboration with Roma communities in London. While this leaflet aims to provide a multi-dimensional look at Roma culture and beliefs, it is important to remember that the Roma community is very diverse. This information offers a starting point in learning about this community.

For more information, please contact Daria Ferranti at Roma Support Group (daria@romasupportgroup.org.uk) or visit our website: www.romasupportgroup.org.uk.

Who are the Roma?

Identity and Origins

- The Roma are the largest ethnic minority group without their own state in Europe. They have their origins in the Punjab and Rajasthan areas of India and began migration out of India approximately 1000 years ago.
- Many Roma in Western Europe are migrants from countries such as Poland, Slovakia, Romania, Czech Republic, Lithuania, Latvia and the former Yugoslavia.
- Though frequently associated with English Gypsies and Irish Travellers, the Roma are a distinct (and diverse) community.

History

- For centuries the Roma maintained a nomadic lifestyle but were forced to settle under the communist regimes of Eastern Europe.

- The Roma first came to the UK as asylum seekers and since the EU accessions of 2004 and 2007 have been coming to the UK as economic migrants.
- They have faced centuries of discrimination, persecution and forced assimilation.
- In many countries they remain marginalised, experiencing barriers to employment, education and health services.

Health Perceptions in the Roma Community

General Health Perceptions

Health is considered to be an unclean subject, often not to be discussed even with close family members. Roma who become health professionals or work in other health-related occupations – such as health advocacy or interpreting – can be treated as unclean and ostracised from the rest of the community.

Some examples of health-related taboos you may encounter in your work with Roma include:

- Subjects related to sexual or reproductive health are considered suitable for discussion only in single-gender groups.
- Health is traditionally not discussed in groups of Roma in which an age gap of more than 10 years exists between any group members.

Attitudes to Mental Health

Mental health has traditionally been a taboo subject within Roma communities, and it is rarely discussed out of fear of stigmatisation.

Communicating about mental health

- Roma may talk about being sad or feeling down in relation to specific problems in their lives. In these cases it is acceptable to say that someone is depressed.
- Some may talk about ‘problems with the head’ or being ‘crazy’ instead of recognising specific mental health conditions.
- Younger members of the community tend to have greater awareness of mental health issues.

The social context of mental health

- Many Roma community members have a strong belief in the genetic transmission of mental health issues, which can lead to diminished marriage prospects both for people suffering from mental health problems and their family members.
- Alcohol abuse is viewed as a social activity and often not treated as an addiction.
- Many Roma community members deny the existence of drug addiction within their tribe or family.
- Victims of rape and domestic violence rarely discuss their traumas out of fear of being subjected to stigma associated with these experiences.

Seeking Help for Mental Health Problems

Roma often try to hide the fact that they are suffering from mental health problems, even from close family members. Once the family is aware of a mental health problem, they will attempt to conceal the problem, only seeking professional help if they become unable to cope. This creates long delays in accessing mental health services.

Issues in Accessing Services

Language

- Many Roma community members speak Romanes (the Roma language) as a first language and later learn the language of countries in which they reside.
- There are many different dialects of Romanes, and although the dialects share a common core, some are so different as to be considered distinct languages.
- There is no specific vocabulary in Romanes for describing certain emotions and parts of the body.

Communicating through interpreters

- Roma patients – even those who speak English – often need interpreters to help explain health-related information.
- The patient-interpreter relationship is very sensitive. There can be an element of mistrust between the Roma patient and a non-Roma interpreter due to experiences in their countries of origin.
- Non-Roma interpreters may not be aware that a Roma patient is speaking a second (or third) language.

- Roma patients may be reluctant to discuss health-related taboo subjects with a Roma interpreter. Particularly if the consultation will address mental or reproductive health, employing a non-Roma interpreter may stimulate more open discussion.

Discrimination, distrust and low self-esteem

- Many Roma community members in the UK have had negative experiences of using health services in their countries of origin.
- Roma may be reluctant to talk about sensitive topics related to health or to fill in questionnaires, fearing unanticipated consequences.

Limited knowledge

- Roma patients may have a limited understanding of which services are available and of the correct methods for obtaining referrals to specialist services.
- They may not be aware of their right to access certain services.

Working with Roma Patients

Some points to keep in mind when building trusting relationships with Roma patients include:

- ➢ Break information into manageable chunks and check regularly for understanding.
- ➢ Avoid jargon and medical terminology, as patients may be reluctant to ask for clarification of terms they do not understand.
- ➢ Coordinate with interpreters to ensure that they understand patient’s language support needs.
- ➢ Maintain eye contact to demonstrate respect; looking too frequently at notes or a computer may be considered offensive.
- ➢ Be clear about how you are going to use any personal information the patient provides in the course of consultation.
- ➢ Explain the purpose of referrals and inform patients of what to expect.

Roma Mental Health Advocacy Project

Are you working with Roma patients who may need additional support in accessing health services?

We can help!

Support for the Roma Community

- Conducting face-to-face health advocacy sessions – assisting patients in communicating with health professionals, understanding referrals and requesting interpreters
- Providing information on mental health issues and signposting to relevant services
- Organising monthly peer support group meetings for community members to learn about and discuss mental health issues

Support for Professionals Working with Roma

- Delivering training sessions on Roma culture and health
- Providing informational materials on health in Roma communities
- Accepting referrals from health professionals with patients who may benefit from our project

Call or email Sarah, Szymon or Edyta for more information:

Sarah Zawacki – Mental Health Advocacy Coordinator
sarah@romasupportgroup.org.uk
020 7511 8245

Edyta Gach – Mental Health Advocate
edyta@romasupportgroup.org.uk

Szymon Glowacki – Mental Health Advocate
szymon@romasupportgroup.org.uk

8.4 Evaluation questionnaire for Project staff

1. How would you describe the involvement of the Mental Health Project with other RSG projects? Do you think the projects collaborated well together? What worked and what didn't?

2. Do you think that the project made it easier for beneficiaries to access mental health services? What would you say were the key barriers and enablers to access?

3. How would you describe the impact of the project in empowering beneficiaries to use mental health services? Would you change anything about our methods?

4. Do you think that the project improved beneficiaries' understanding of mental health issues? What worked and what didn't?

5. Do you think that the project improved beneficiaries' satisfaction with mental health services? What were the sources of satisfaction and dissatisfaction? Could we have done anything differently to improve satisfaction?

6. How would you describe the project's engagement with mental health professionals? What would you say were the key barriers and enablers to contact?

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